

Aspirations and outcomes for people with autism spectrum disorders in
emerging adulthood

Zoe Huntley

D.Clin.Psy thesis (Volume 1), 2013

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name:

Date:

Overview

This thesis focuses on subjectively valued outcomes and aspirations for young adults with autism spectrum disorders (ASD). Part 1 reviews research literature examining adulthood outcomes for people with ASD. The review highlights the on-going needs of adults with ASD, who are commonly reported to have low levels of independence, high rates of unemployment and high levels of social isolation. None of the reviewed studies considered the young adults' own perspectives on their current circumstances or future in a meaningful way.

Part 2 reports a qualitative study using framework analysis to explore the outcomes and aspirations of young adults with ASD and their parents. Semi-structured interviews highlighted families' varied outcomes and aspirations, beyond the stereotyped outcomes often represented in the literature. A framework for understanding and assessing outcomes is proposed, which may be developed into a tool for clinicians and other professionals working to support adults with ASD to meet their own personally valued goals.

Part 3 discusses some of the challenges of using qualitative methodology with people with ASD, and considers the implications of the findings for service provision. Similarities between working with typically developing young adults and young adults with ASD are considered, and the barriers in achieving personally valued outcomes for adults with ASD are highlighted. These include assumptions made by others based on a limited, stereotyped understanding of ASD which may lead to young adults' own valued goals being overlooked, and idiosyncratic preferences that may place people with ASD at risk of being coerced into inappropriate or uncomfortable activities. The importance of focusing on individuals' own valued outcomes is emphasised.

Contents

Overview	3
List of Tables	6
List of Figures.....	6
Acknowledgments	7
Part 1: Literature Review.....	8
Abstract.....	9
Aim.....	9
Method	9
Results	9
Conclusions	9
Introduction	10
Research questions	11
Method	11
Inclusion criteria.....	11
Search strategy	12
Results	14
Quality and relevance assessment	14
Core ASD features	16
Other psychosocial outcomes.....	31
Discussion.....	42
References	47
Part 2: Empirical Paper.....	57
Abstract.....	58
Aims	58
Method	58
Results	58
Conclusions	58
Introduction	59
Method	62
Overview	62
Service-user consultation	62
Context	62
Participants	63
Ethical approval.....	63
Recruitment procedure	63
Measures.....	66
Procedure.....	68
Analytic procedure	69
Disclosure of researcher's perspective	70
Results	71
Results from the HADS	71
Framework analysis.....	72
Respondent validity.....	93
Discussion.....	93

Limitations	98
Proposed framework for understanding and assessing aspirations and outcomes	100
Implications	102
References	103
Part 3: Critical appraisal.....	109
Introduction	110
Phenomenological research and ASD	110
Developing qualitative measures for people with ASD	110
Involving service users in the research process	111
Mothers as a primary point of contact.....	113
Conflicting views between parents and young adults	115
One-off interviews cannot tell the full story	115
Implications and applications of findings	116
Using these findings in UK statutory service provision.....	116
Are young adults with ASD different to typically developing young adults?.....	118
Conclusion.....	119
References	119
Appendices	121
Appendix 01: Quality and relevance assessment scale.....	122
Appendix 02: Studies excluded from literature review	125
Appendix 03: Ethical approval	127
Appendix 04: Ethics committee receipt of amended documents	132
Appendix 05: Invitation letter (young person)	134
Appendix 06: Invitation letter (parent)	136
Appendix 07: Interview schedule (young person)	138
Appendix 08: Interview schedule (parent).....	143
Appendix 09: Participant details questionnaire	148
Appendix 10: Hospital Anxiety and Depression Questionnaire (HADS)	151
Appendix 11: Information sheet (young person).....	153
Appendix 12: Information sheet (parent)	158
Appendix 13: Consent form.....	163
Appendix 14: Example of coded transcript	165
Appendix 15: Respondent validation example (young person).....	168
Appendix 16: Respondent validation example (parent)	171
Appendix 17: Extract from thematic matrix	174
Appendix 18: Respondent validation form	177

List of Tables

Part 1: Literature review

Table 1. Search terms	13
Table 2. Quality and relevance ratings.....	15
Table 3. Summary table of reviewed studies	17
Table 4: Frequency of relationships reported in reviewed studies.....	24
Table 5. Employment and education for adults with ASD	32
Table 6: Residential status of adults with ASD	35
Table 7. Mental health problems in adults with ASD	38

Part 2: Empirical paper

Table 1: Participant details.....	64
Table 2. HADS Anxiety and depression scores	71
Table 3. Framework analysis and frequency of themes	73

List of Figures

Part 2: Empirical paper

Figure 1. Recruitment and eligibility flow chart.....	66
Figure 2. Proposed framework for understanding and assessing outcomes for people with ASD	101

Acknowledgments

I am grateful to each of the young adults and parents who have taken part in this study, given up their time and shared their experiences with me. I hope that I have been able to capture their experiences in the way that they hoped I would. I would like to thank my supervisors, Dr. Will Mandy and Prof. Chris Barker, whose expertise and encouragement has been invaluable. Thanks also to Holly Judge, Jasmine Taylor and the clinic staff who have supported this project.

Part 1: Literature Review

Adulthood outcomes for people with autism spectrum disorders

Adulthood outcomes for people with autism spectrum disorders

Abstract

Aim

To review current understanding of adulthood outcomes for people with autism spectrum disorders (ASD).

Method

PsycInfo and OVID MEDLINE searches for studies of adult outcomes for people with ASD and an IQ above 70 identified 25 articles meeting quality and relevance criteria for review.

Results

ASD diagnoses were stable over time, though ASD sub-type diagnoses were not. Improvements were observed in verbal communication but not in other areas. Adults with ASD were at risk of social isolation, mental health difficulties and unemployment, though participants had rarely been asked about their own aspirations or concerns for adulthood.

Conclusions

ASD-related difficulties may become less noticeable in adulthood for higher functioning individuals, although they experience on-going difficulties and poor psychosocial outcomes. The importance of moving towards person-centred concepts of outcome is emphasised.

Introduction

Adults with autism spectrum disorders (ASD) have historically been neglected in ASD research in favour of investigating childhood assessment, diagnosis and intervention. Many studies about ASD in adulthood focus on those with profound autism and/or associated learning disability. However, around fifty percent of individuals who meet diagnostic criteria for ASD have an IQ within the normal range or above (Baird et al., 2006) and may have very different needs, experiences and outcomes to those with a learning disability.

Since the 1970s, outcome studies in ASD have moved towards providing composite ratings of outcomes on a continuous scale of very good to very poor (Howlin & Moss, 2012) based on levels of independence, occupation and relationship status. Howlin and Moss's (2012) review of adulthood outcome studies in ASD concluded that many adults with ASD, including those with normal IQ, experience difficulties or disadvantage in a range of areas, including employment, social relationships, health and quality of life.

However, a limitation of using composite scales in outcome research is that an overall composite rating gives little information about a person's desired or valued outcomes. An individual could score highly on objective outcome ratings, such as being employed, living independently and having frequent social contacts, whilst not achieving their own valued goals. A person with ASD might prefer a more solitary lifestyle to frequent social contact, for example. Whilst composite outcome measures might be more easily comparable across studies than other methods, they lose rich data along the way, with particularly poor outcomes in one area masked by better outcomes elsewhere. In recognition of these limitations, other clinical specialities such as psychosis and learning

disability have moved towards person-centred planning and consideration of individual goals and roles (e.g. Department of Health, 2010) over externally imposed concepts of a “good” outcome, but this approach has not been adopted for people with ASD.

This review aimed to address limitations in ASD outcome research by examining recent research in each area of outcome rather than using composite scoring, and by reviewing what is known about person-centred outcomes for adults with ASD.

Research questions

This review addressed two questions:

1. What are the outcomes for people with ASD in adulthood?
2. What is known about valued outcomes from the perspective of adults with ASD?

These questions were addressed with a review of studies of adults with ASD from the past ten years. This time period was chosen as longitudinal studies from longer ago relied on very different diagnostic methods that may have been vague or unreliable (Henninger & Taylor, 2012) in comparison to contemporary assessment protocols, to limit results to a manageable quantity and to ensure the review focuses on current knowledge and best practice.

Method

Inclusion criteria

This review included studies meeting the following criteria: (1) the target population included adults (over 18) diagnosed with an ASD (2) the sample included individuals with an IQ (full-scale or estimated) of 70 or above (3) the article reported results from measures related to psychosocial outcomes (4) the study did not involve

intervention or experimental manipulation of factors related to outcome (5) the study was published in a peer-reviewed journal (6) the study was reported in English (7) the study was published between January 2002 and April 2012. Studies meeting these criteria were subjected to formal quality and relevance assessment. At this stage, an additional inclusion criterion was applied: (8) the study was given a rating of “high” or “medium” in a quality and relevance assessment measure.

As recent changes to diagnostic criteria in DSM-5 (American Psychiatric Association, 2013) have removed distinctions between ASD diagnoses (e.g. autism, Asperger’s Syndrome, pervasive developmental disorder – not otherwise specified (PDD-NOS)), this review includes studies of participants with any ASD diagnosis. For the purpose of this review, the term “learning disability” is used to refer to participants with an IQ below 70, and an IQ in the “normal range” refers to those with an IQ of 70 or above. Studies not reporting sample IQ were included if relevant. As this review focused on ASD across the range of intellect and not on outcomes for adults with a learning disability, studies in which every participant met criteria for a learning disability were not included.

Search strategy

To identify studies meeting the inclusion criteria, PsycInfo and Ovid MEDLINE databases were searched for entries containing the following terms (or synonyms) in the title or keywords: (1) adult, (2) outcome, (3) autism spectrum disorders (Table 1). The search terms selected were intentionally broadly inclusive, so that studies considering a wide range of outcomes would be identified. Studies with titles or keywords relating to interventions were excluded, to avoid making conclusions about outcomes based on samples selected to include only those requiring interventions.

Table 1. Search terms

	Terms	Results
1	(adult* or life* or maturity or aging or (grow* adj up)).m_titl.	478,074
2	outcome.mp.	11,084,600
3	(success* or difficult* or problem* or consquen* or lifestyle or outcome* or effect* or result* or risk* or function* or employ* or activit* or educat* or hous* or social* or relationship* or behavio* or abilit* or independ* or depend* or living or friend* or leisure or job* or quality or recover*).m_titl.	4,628,732
4	Autism.mp. or exp Autism/	42,435
5	((autis* or asperger* or neurodevelop*) adj disorder) or (pervasive adj development*) or PDD* or HFA or (childhood adj disintegrative) or (social adj communication) or ASD).m_titl.	3,832
6	2 or 3	5,383,158
7	4 or 5	44,085
8	1 and 6 and 7	897
9	(interven* or program* or course or therap* or workshop or strateg* or treat* or group* or medic* or trial).mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, tc, id, tm]	9,361,863
10	8 not 9	266
11	limit 10 to (human and adulthood <18+ years> and "300 adulthood <age 18 yrs and older>" and "0110 peer-reviewed journal" and English and human) [Limit not valid in Ovid MEDLINE(R); records were retained]	184
12	remove duplicates from 11	129

Results

The PsycInfo and OVID MEDLINE search identified 129 studies, 91 of which were within the specified date range. An additional 12 studies cited in the recent review by Howlin & Moss (2012) and within the date range were also identified, giving a total of 103 articles. Abstracts of these 103 articles were screened according to the inclusion criteria. Thirty-six studies met criteria 1-7 and were included in formal quality and relevance assessment. Exclusion reasons for the remaining 67 are given in Appendix 02.

Quality and relevance assessment

Many tools are available to assess the quality of intervention studies and studies with randomised designs, but fewer for cohort or cross-sectional studies similar to those reviewed here. The Newcastle-Ottawa Scale (NOS) (Wells et al., 2004) was developed for assessing quality of non-randomised studies for the purposes of systematic reviews and meta-analyses, and so was chosen as the most appropriate scale to adapt for this review. The NOS offers a star rating system for cohort studies on the basis of participant selection, group comparability and outcome measurement criteria. This scale was adapted to assess both cohort and cross-sectional studies specific to this review (Appendix 01). An overall rating system of quality for the current review was developed based on NOS star ratings. Studies scoring seven stars or more were rated as “high” in both relevance and quality, studies scoring five to six were rated as “medium” and studies scoring less than five were rated as “low”. Eleven studies with a “low” rating (Lahaie et al., 2006; Mazefsky, Folstein, & Lainhart, 2008; McCabe & Wu, 2009; Munesue et al., 2008; Nishimura, Rutherford, & Maurer, 2008; Orsmond, Krauss, & Seltzer, 2004; Shtayermman, 2008, 2009; Vlamings, Stauder, Son, & Mottron, 2005; Whitehouse,

Watt, Line, & Bishop, 2009; Yamamoto & Nihei, 2008) were excluded, leaving 25 studies for review (Table 2).

Table 2. Quality and relevance ratings

Study		Selection	Control	Outcome	Overall rating
<i>Longitudinal studies</i>					
Billstedt et al.	2005	***	-	****	High
Cederlund et al.	2008	***	*	***	High
Eaves & Ho	2008	**	*	**	Medium
Farley et al.	2009	**	*	***	Medium
Gillespie-Lynch et al.	2012	**	*	***	Medium
Howlin et al.	2004	***	*	****	High
Hutton et al.	2008	***	-	****	High
Krauss et al.	2005	**	-	***	Medium
Orsmond et al.	2006	**	*	**	Medium
Shattuck et al.	2007	**	*	**	Medium
Smith et al.	2008	**	*	**	Medium
Taylor & Seltzer	2010	**	*	***	Medium
Taylor & Seltzer	2011a	**	*	**	Medium
Taylor & Seltzer	2011b	**	*	***	Medium
<i>Cross-sectional studies</i>					
Baron-Cohen & Wheelwright	2004	***	*	**	Medium
Baron-Cohen & Wheelwright	2003	***	*	**	Medium
Baron-Cohen et al.	2003	**	*	**	Medium
Chowdhury et al.	2010	**	*	**	Medium
Engstrom et al.	2003	**	*	***	Medium
Hofvander et al.	2009	***	*	***	High
Lai et al.	2011	***	*	***	High
Marriage et al.	2009	***	*	**	Medium
Renty & Roeyers	2006	**	*	**	Medium
Saldana et al.	2009	***	-	**	Medium
Taylor et al.	2008	*	*	***	Medium

The twenty-five papers reported a range of outcomes, considered here in two broad categories; (1) outcomes related to core ASD features, and (2) other

psychosocial outcomes (Table 3). Studies were classified as examining core ASD features if they investigated stability of ASD diagnoses over time, or any of the elements considered either in the traditional “triad of impairments” approach to diagnosis (social communication, interaction, imagination) (Wing & Gould, 1979) or the new “dyad of impairments” in DSM-5 (social communication/interaction and fixed interests/repetitive behaviours) (American Psychiatric Association, 2013). Core ASD features are considered in this review under four headings:

- i) Stability of ASD diagnosis
- ii) Social communication
- iii) Social interaction (including social imagination and theory of mind)
- iv) Fixated interests or repetitive behaviours

The other psychosocial outcome categories reported in Table 2 are the most commonly reported psychosocial outcome domains in the reviewed studies: cognitive ability; independent living; employment and education; quality of life and mental health.

Core ASD features

Stability of ASD diagnosis. Twelve studies report adulthood ASD status or severity, often using validated parent-report assessments such as the Autism Diagnostic Interview – Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994) or Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing, Leekham, Libby, Gould, & Larcombe, 2002) and behavioural observation tools such as the Autism Diagnostic Observation Schedule – Generic (ADOS-G) (Lord et al., 2000), though findings from these measures are not always reported in detail (e.g. Howlin, Goode, Hutton, & Rutter, 2004). Four of the twelve articles report data from

Table 3. Summary table of reviewed studies

Study	N	Male (%)	Age (yrs.) Mean (range)	IQ	ASD related outcomes				Other psychosocial outcomes					
					Stability of diagnosis	RSB	Social communication	Social interaction	Cognitive	Independent living	Employment & education	Quality of life	Mental health	
Longitudinal studies														
Billstedt et al. ^g	2005	120	70.0	25.5 (17-40)	Mixed	Y	-	-	-	Y	-	-	-	Y
Cederlund et al. ^g	2008	140	100.0	23.0 (16-36)	Mixed	Y	-	-	Y	Y	-	Y	-	Y
Eaves & Ho	2008	48	77.1	24	Mixed	Y	-	-	Y	Y	Y	Y	Y	Y
Farley et al.	2009	41	92.7	32.5 (22-46)	Normal range	Y	-	-	Y	Y	Y	Y	-	Y
Gillespie-Lynch et al.	2012	20	ns	26.6	Mixed	Y	Y	Y	Y	-	Y	Y	-	-
Howlin et al.	2004	68	89.7	29.33 (21-49)	Mixed	Y	-	-	Y	Y	Y	Y	-	-
Hutton et al.	2008	135	77.0	34.9 (21-57)	Mixed	-	-	-	Y	-	Y	Y	-	Y
Krauss et al. ^a	2005	133	70.7	31.9	Mixed	-	-	-	-	-	Y	-	-	-
Orsmond et al. ^a	2006	202	73.0	19.8 (11-48)	Mixed	-	-	-	Y	-	-	-	-	-
Shattuck et al. ^a	2007	241	75.5	22.0 (10-52)	Mixed	Y	Y	Y	-	-	Y	-	-	-
Smith et al. ^a	2008	149	75.5	19.9 (11-49)	Mixed	-	-	-	Y	-	-	-	-	-

						ASD related outcomes				Other psychosocial outcomes					
Study	N	Male (%)	Age (yrs.) Mean (range)	IQ		Stability of diagnosis	RSB	Social communication	Social interaction		Cognitive	Independent living	Employment & education	Quality of life	Mental health
Taylor & Seltzer ^a	2010	242	73.1	16.3 (10-24) ^b	Mixed	Y	Y	Y	Y		-	Y	Y	-	-
Taylor & Seltzer ^a	2011b	170	75.9	16.7 (11-22)	Mixed	-	-	-	Y		-	Y	-	-	-
Taylor & Seltzer ^a	2011a	66	80.0	22.98 (19-26)	Mixed	Y	-	-	-		-	-	Y	-	Y
<i>Cross sectional studies</i>															
Baron-Cohen & Wheelwright ^c	2003	68	75.0	34.3 (14-63)	Normal range	-	-	-	Y		-	-	-	-	-
Baron-Cohen & Wheelwright ^c	2004	90	72.2	34.2 (15-60)	Normal range	-	-	-	Y		-	-	-	-	-
Baron-Cohen & Wheelwright ^c	2003	47	70.2	38.1	Normal range	-	Y	-	Y		-	-	-	-	-
Chowdhury et al.	2010	34	97.1	22.5 (19-28)	Normal range	-	Y	-	-		-	-	Y	-	-
Engstrom et al.	2003	16	56.3	31.4 (23-46)	Normal range	-	-	-	Y		-	Y	Y	-	-
Hofvander et al.	2009	122	67.2	29 ^d (16-60)	Normal range	Y	-	-	Y		-	Y	Y	-	Y
Lai et al.	2011	62	53.2	M 27.0 / F 26.9	Normal range	Y	Y	Y	Y		Y	-	-	-	Y
Marriage et al.	2009	80	80.6	21.4 (19-37) ^e	Normal range ^f	-	-	-	Y		-	-	Y	-	Y

						ASD related outcomes				Other psychosocial outcomes				
Study	N	Male (%)	Age (yrs.) Mean (range)	IQ	Stability of diagnosis	RSB	Social communication	Social interaction	Cognitive	Independent living	Employment & education	Quality of life	Mental health	
Renty & Roeyers	2006	58	74.1	28.34 (18-53)	Normal range	-	-	-	Y	-	Y	Y	Y	-
Saldana et al.	2009	74	85.0	24.6 (18-40)	ns	-	-	-	Y	-	Y	Y	Y	-
Taylor et al. ^a	2008	20	60.0	34 (19-60)	Normal range	Y	-	-	Y	-	-	-	-	-
Total studies considering:						12	7	5	20	6	13	14	3	9

^a Subsample of families from the same longitudinal study (N=406). ^b At Time 1, study follows participants over five time points over ten years. ^c Articles report data from related sample. ^b Median age. ^c Age reported for 45 participants. ^f Plus an additional group with ID. ^g Articles report data from related sample.

overlapping samples, taken from one large-scale longitudinal study (Shattuck et al., 2007; Taylor, Target, & Charman, 2008; Taylor & Seltzer, 2010, 2011a), and two others report data from the same sample at different time points (Billstedt, Gillberg, & Gillberg, 2005; Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008).

Since the duration of ASD is life-long, it is expected that diagnoses will be stable, and this is evidenced in the reviewed studies, particularly in diagnoses based on validated parent interview measures (e.g. Billstedt et al., 2005; Cederlund et al., 2008; Farley et al., 2009; Gillespie-Lynch et al., 2012). Persistence of ASD symptoms is also reported from childhood into adolescence on questionnaire measures (Eaves & Ho, 2008). However, some studies suggest some improvement in ASD symptoms between childhood and adolescence. For example, Gillespie-Lynch et al. (2012) report ADI-R scores across three different time points, at mean ages 11.7, 18.3 and 26.6 years respectively, and find some improvements (i.e. lower ADI-R social subscale scores) in symptoms across the first two time points, though these were not maintained, and scores deteriorated into adulthood. A pattern of improvements in ASD symptoms that are not maintained is also reported elsewhere (Taylor & Seltzer, 2010, 2011a). Further, when changes over time do occur, they have not been found to influence diagnostic classification (Shattuck et al., 2007), suggesting that observed changes may not be clinically meaningful and that ASD diagnoses remain reliable.

However, prior to DSM-5, most individuals were given a diagnosis of a more specific ASD, such as Autism or Asperger's Syndrome, and reliability of these more specific categories within ASD is poor in the reviewed studies. For example, in a prospective follow up of 120 adults with ASD and mixed IQ (Billstedt et al., 2005), despite 95.4% of those coming into the study with a diagnostic of "autistic disorder"

(AD) or “atypical autism” still meeting criteria for one of these diagnoses on a parent interview measure, 86% of those entering the study with an atypical autism diagnosis now met AD criteria instead. A later follow up of this sample (Cederlund et al., 2008) also reached similar conclusions; all participants met ASD criteria on the diagnosis, but participants often moved between the diagnostic categories of AD, atypical autism and Asperger Syndrome, with the atypical autism category being particularly likely to change. This indicates high reliability of the ASD category, but not of the sub-divisions within it. Queries about utility, validity and reliability of sub-divisions within ASD are strengthened by the cross-sectional findings of Hofvander et al. (2009), who found that all ASD diagnostic criteria were prevalent across diagnostic categories.

Stability of diagnosis has been reported as lower when assessment is based on behavioural observations than parent-interview. In Farley et al.’s (2009) follow up of adults with ASD and normal range IQ, six of 37 participants (16%) did not meet ASD criteria on the ADOS-G, despite only one of these being reported not to have significant ASD features. This may indicate that behavioural observations are less sensitive to adult difficulties, possibly as higher functioning individuals may learn appropriate behaviour, which could make difficulties appear more subtle and difficult to detect. Reduced sensitivity of observational measures (compared to parent interview) is also reported elsewhere (Lai et al., 2011; E. Taylor et al., 2008).

The reviewed studies indicate that diagnostic protocols in childhood are effective in reliably diagnosing ASD, though diagnoses of specific disorders within the spectrum are unreliable, even when methodologically sound assessment protocols are used. This supports findings of poor diagnostic reliability for ASD subtypes (Lord et al., 2012) and the recent move to one “ASD” diagnostic category in DSM-5

(American Psychiatric Association, 2013). Behavioural observation measures may be less sensitive to ASD in adulthood, highlighting the need for comprehensive assessment using a range of assessment methods. This highlights a challenge in assessing ASD in adulthood; it appears that parent report is important in the assessment process, but is often less readily available in adult services.

Social communication. Social communication deficits can refer to language delay or disorder, but also to other abnormalities, including poor intonation, inappropriate speech for social context (Wing & Potter, 2002) or atypical use of emphatic and descriptive gestures. Social communication skills or outcomes were considered in five studies (Gillespie-Lynch et al., 2012; Lai et al., 2011; Saldana et al., 2009; Shattuck et al., 2007; Taylor & Seltzer, 2010) using a range of assessment measures.

One large-scale longitudinal study found that parent-reported verbal communication improved over time as young people left high school and beyond (Shattuck et al., 2007; Taylor & Seltzer, 2010), a finding supported by Gillespie-Lynch et al.'s (2012) smaller longitudinal investigation using different assessment tools, that found in a sample of twenty individuals with autism, communication skills significantly improved between two time points, between which the majority of their sample reached adulthood (T2 mean age 11.7 years, T4 mean age 26.6 years). These two studies also report non-verbal communication, and both found that non-verbal communication did not consistently improve into adulthood. Similar findings across assessment measures and in multiple longitudinal studies strongly suggests that these findings of improving verbal communication but not non-verbal communication are reliable.

Only one study (Lai et al., 2011) considered sex differences in communication. The study found greater deficits in adult communication based on behavioural observation measures, though given concerns about the sensitivity of the such measures and the lack of research in adulthood sex differences, this result must be interpreted with caution. Other evidence reviewed that is too limited to draw firm conclusions includes Saldana et al.'s (2009) finding that many ASD adults had severe communication problems; this study offers limited insight as learning disability was not controlled for and the sample had very mixed verbal ability.

Although it is difficult to reach firm conclusions due to mixed methodologies and the range of communication abilities within ASD, there is evidence in the reviewed studies of verbal improvements into adulthood and persistent difficulties with non-verbal communication. One possible mechanism for this might be that verbal communication is more tangible than non-verbal communication. This more tangible nature might make it more possible for individuals to learn to compensate for verbal than non-verbal communication difficulties, though this cannot be assessed from the reviewed studies.

Social interaction. Social interaction was the most frequently reported outcome variable (Table 3), considered in twenty articles. The results of the review in this area are considered in three sections: social and family relationships; social skills; and social imagination.

Social and family relationships. Proportions of participants having close friendships ranged from 19-33% (Eaves & Ho, 2008; Howlin et al., 2004) with over half having no significant friendships (Howlin et al., 2004) (Table 4). Notably, the assessments of friendships in both Eaves and Ho (2008) and Howlin et al. (2004) were based on parent report of friendships, and it is not known how well this

Table 4: Frequency of relationships reported in reviewed studies

	n	IQ	Formal measure of social interaction / friendships	One or more close friendships (%)	No peer relationships (%)	Current or previous romantic relationship (%)	Never had a romantic relationship (%)
Eaves & Ho 2008	48	Mixed	ns	33	ns	ns	ns
Engstrom et al. 2003	16	Normal range	ns	ns	ns	38	ns
Farley et al. 2009	41	Normal range	Interview for study	ns	ns	14	44
Howlin et al. 2004 ^a	68	Mixed	ADI-R	26	56	ns	ns
			Parent questionnaire	19	51	ns	ns
Hutton et al. 2008	135	Mixed	Informant questionnaire	ns	ns	3 ^b	ns
Renty & Roeyers 2006	58	High functioning ASD	QOL-Q	ns	ns	19	81

^a Provided data from two measures (top row ADI, bottom row composite score). ^b Of the 14 participants living independently. ns = not stated

correlates with adults' own views about the nature and value of friendships. Howlin et al. (2004) used the ADI-R to define relationships, assessing individuals' relationships in terms of selectivity, sharing and self-initiative in seeking contact. Eaves and Ho (2008) used a different measure that also rated friendships according to sharing and mutuality in relationships. It is plausible that relationships may be meaningful and satisfying without meeting these criteria, and so these findings might not represent adults with ASD's perspective on relationships.

Findings of on-going social relationships deficits are however echoed in studies using a range of methodologies, including questionnaires about presence, enjoyment and interest in friendships (Baron-Cohen & Wheelwright, 2003) and a clinical note review (Marriage, Wolverton, & Marriage, 2009). Similarly, Saldana et al. (2009) asked families of seventy-four people with ASD to identify people in the person's social networks who could help with everyday personal care, emotional support or participate in leisure activities. They found that seven percent had only their mother across these areas and around a third had only two people.

Social isolation is reported consistently across methodologies and heterogeneous ASD samples. There is remarkably little discussion in the literature about individuals' preference regarding relationships, and the impact of participants' relationships or isolation on their wellbeing, although Renty and Roeyers (2006) linked the perceived availability of informal support to quality of life for adults with ASD. Some items of the Friendship Questionnaire (Baron-Cohen & Wheelwright, 2003) measure interest in friendships, and so future research with this measure could helpfully report outcomes on specific items as well as overall score.

The mother-child relationship may be of particular significance for young adults with ASD as this may be one of few relationships in their lives, and as

maternal warmth, praise and relationship quality has been linked with reductions in behavioural problems and ASD symptoms. The reviewed studies offer encouraging findings of warmth from parents and attachment security (Taylor et al., 2008), although there may be difficulties in this relationship in later adolescence for those without learning disability (Taylor & Seltzer, 2011a). This could however be a result of healthy adolescent separation from parents in those with higher levels of functioning. Saldana et al. (2009) asked parents to complete the Comprehensive Quality of Life questionnaire (ComQol) (Cummins, 1997) and found that families perceived adults with ASD to be more satisfied with intimacy with family than intimacy with friends. However, the quality of relationships reported in reviewed studies is heterogeneous and measures used (speech samples, the Positive Affect Index rating scale and parent-report) may be vulnerable to effects of social desirability. This might be particularly in the context of stigma for mothers of children with ASD following the now discredited reports of “refrigerator mothers” as responsible for ASD that emerged in the 1950s (e.g. Bettelheim, 1967).

The reviewed studies report that just 3-38% of adults with ASD have had a romantic or intimate relationship (Engstrom, Ekstrom, & Emilsson, 2003; Farley et al., 2009; Hutton, Goode, Murphy, Le Couteur, & Rutter, 2008; Renty & Roeyers, 2006). However, intimate relationships have not consistently been linked to improved quality of life (Renty and Roeyers, 2006) and a preference for having relationships should not be assumed; Farley et al. (2009) report that 41% of parents of adult children with ASD who had never had a romantic relationship believed their child would not want one.

Social interaction skills. Given the lifelong nature of ASD, it is expected that deficits in social interaction skills will persist into adulthood. However, little is

known about how these skills develop over time. Some improvements were reported in ASD symptomatology, including social reciprocity, non-verbal and verbal communication, in one large scale longitudinal study before high school exit (Taylor & Seltzer, 2010) using the parent-report ADI-R. However, for all scales except non-verbal communication, these improvements slowed after high school exit, and other studies also suggest on-going difficulties with social interaction in adulthood (Gillespie-Lynch et al., 2012; Smith, Greenberg, Seltzer, & Hong, 2008). A comprehensive assessment of 122 adults with ASD diagnosed in childhood also found that almost all continued to meet both DSM-IV (American Psychiatric Association, 1994) and Gillberg & Gillberg (1989) social interaction deficit criteria in adulthood (Hofvander et al., 2009).

In contrast, Lai et al. (2011) reported combined social and communication scores from the ADOS-G behavioural observation. They found that just six of twenty nine females with ASD and nineteen of thirty three males met the “autism spectrum” cut off for the social and communication subscale. However, as social interaction improvements are rarely reported in the literature using other methods, this seems likely to reflect either lack of sensitivity of the ADOS-G or findings confounded by improving communication scores.

Social imagination. Social imagination refers to the capacity to predict the consequences of one’s own actions for self and others (Wing, Gould, & Gillberg, 2011), which develops throughout childhood in healthy populations. Social imagination does not appear in ICD-10, DSM-IV or DSM-5 diagnostic criteria for ASD, although its omission has been criticised (Wing et al., 2011) as it is widely reported as a feature of ASD in the literature.

Three studies report results of the Empathy Quotient (EQ) self-report questionnaire (Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003; Baron-Cohen & Wheelwright, 2003; Lai et al., 2011). Similar results are reported for across the articles, with adults with ASD scoring 18.9-22.7, compared to control scores of 42.1-42.2 (higher score indicates more highly developed empathy skills). No difference was identified between male and female scores in a HFA and AS sample (Lai et al., 2011). The EQ is used widely in research settings and as a screening tool for ASD in clinical practice. However, as a questionnaire measure it is limited in its ability to describe impairments in complex social interactions. Further, this method relies on participants having enough insight into their relationships to provide valid and reliable self-report ratings. Therefore, tasks assessing social imagination and related abilities may be a more valid indicator of impairment.

The “Reading the Mind in the Eyes” test (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) is one such task. This mentalizing task requires participants to infer mental states from photographs of people’s eye area. Participants with HFA and Asperger Syndrome achieved mean scores of 22.3 (males) and 22.7 (females) of a possible 36 in one study (Lai et al., 2011), and 25.6 in another (E. Taylor et al., 2008). No control data is given, but other studies not reviewed here report mean scores in IQ-matched controls to be 30.9 (Baron-Cohen et al., 2001). This suggests that theory of mind and social imagination performance is poorer in people with ASD than healthy controls, though it is unclear whether this is a clinically meaningful or statistically significant difference. Imagination and empathy scores are also given in the ADOS-G (Lord et al., 2000), which was widely used in the studies reviewed here, but scoring is rarely reported in detail.

Overall indications suggest on-going social imagination impairment in adulthood for people with ASD. This may have a significant impact on ability to get along with others and form relationships, although this has not been found to be associated with attachment security (Taylor et al., 2008). Possible impact of social skills training and other educational programmes developed for these difficulties is not considered here and as none of the reviewed studies report childhood ratings, change over time is not assessed.

Repetitive and stereotyped behaviours (RSBs). Seven of the reviewed articles considered RSBs in adulthood (Baron-Cohen et al., 2003; Chowdhury, Benson, & Hillier, 2010; Gillespie-Lynch et al., 2012; Lai et al., 2011; Saldana et al., 2009; Shattuck et al., 2007; Taylor & Seltzer, 2010), of which RSBs were the primary focus of one (Chowdhury et al., 2010), and systematising (the drive to analyse variables and derive the underlying rules governing a system's behaviour) another (Baron-Cohen et al., 2003).

The reviewed articles present inconsistent data about the persistence of RSBs over time. Gillespie-Lynch et al. (2012) found no change in RSBs over three time points fifteen years apart (from mean age 11.7-26.6 years) based on validated parent interview measures with a mixed ability sample. Further, Saldana et al. (2009) report that forty-nine percent of their sample of seventy-four individuals with ASD to have “intense and maladaptive stereotypes” in their behaviour according to a brief questionnaire measure. Another prospective follow-up study (Shattuck et al., 2007) of adults with normal IQ at mean age twenty two years did find “clinically visible” improvements in RSBs over a four and a half year period, though this was not maintained in Taylor and Seltzer's (2010) follow up of the sample. Chowdhury et al. (2010) found that current ratings of RSBs by parents of adults with ASD and normal

IQ were 24.4% lower than lifetime ratings, though their sample were not assessed at multiple time points.

A complex picture of change might explain varied findings in studies of RSBs over time in RSBs. Despite Taylor and Seltzer's (2010) finding that RSB improvements were not maintained, their study of 242 individuals found that particular RSB traits were more persistent than others; unusual preoccupations and unusual sensory interests were particularly persistent, with less than twenty percent of those rated "symptomatic" in lifetime ratings scoring "asymptomatic" in current ratings. They also found that self-injurious behaviours were notably more persistent than other RSBs. Therefore, considering remittance or persistence of RSBs as a general category might be inappropriate, with more specific measures required. In addition, some RSBs might be more overtly identifiable than others (e.g. repetitive behaviours are more noticeable than fixated interests) and so might be more reliably recorded in studies.

Taylor and Seltzer's (2010) regression analyses further suggested that those with learning disability had higher rates of RSBs. However, this may indicate that RSBs are more easily observed in these participants or that those with higher IQ might learn to restrict their behaviours or to talk about their interests less, making their presence more subtle. Lai et al. (2011) investigate sex differences in adults with ASD. Although they reported higher scores for adults using some measures, these differences were not maintained once corrections for multiple comparisons were made.

The implicit assumption of many of the reviewed studies is that RSBs are an inherently impairing and undesirable aspect of ASD. However, it is plausible that RSBs, and particularly fixated interests, might be rewarding for an individual in a

positive way, such as by providing opportunities for enjoyment, meeting others or finding valued employment. Baron-Cohen et al. (2003) conceptualising these features as the consequence of superior systematising (in line with extreme male brain theories of ASD (Baron-Cohen & Hammer, 1997) in adults with ASD, and find higher scores on the “Systematising Quotient” (SQ) questionnaire in forty-seven adults with ASD than controls.

The reviewed studies do not present convincing evidence of changes in RSBs as people with ASD reach adulthood. Evidence for improvement is inconsistent, and may be explained by a reduction in the overtness of RSBs such that, particularly in individuals with higher IQ, RSBs may become more subtle. It is not clear whether RSBs always cause impairment or distress.

Other psychosocial outcomes

Employment and education. Fourteen studies report education and/or employment data (Table 5), mostly as basic information in the sample demographics rather than an outcome measure. Substantial variation is seen in the proportion of adults with ASD in work or education, with rates of participants not in work or education ranging from below 10% (Farley et al., 2009) to 68.2% (J. Taylor & Seltzer, 2011b). In some studies this may be influenced by the inclusion of participants with a learning disability, though in studies reporting data from participants with an IQ score of seventy or over, rates of participants not in work or education also range from 9.8% to 59.0% (Farley et al., 2009; Hofvander et al., 2009). This suggests that some groups of adults with ASD struggle to engage with or maintain work or education, and that this is not fully explained by IQ differences.

There was little discussion about career options or ambitions in the reviewed literature, despite several studies reporting a number of participants who had

Table 5. Employment and education for adults with ASD

Study	Date	N	IQ	Employed (%)	Supported or sheltered employment (%)	In education (%)	Educational attainment	Not in education and not employed (%)
Cederlund et al.	2008	140	Mixed	Autism: 1.4 AS: 10.0	ns	ns	Autism: 0% university, 8.6% in or currently finished high school. AS: 14.3% did university studies/had a degree. 47.1% were in or had currently finished, high school	Autism: 18.6 AS: 17.1
Eaves & Ho	2008	48	Mixed	56.3 had been employed (inc. sheltered)	56.3 had been employed (inc. sheltered)	ns	33% could not read, 23% read at grade 9-13 level. 29% attended post-secondary, 2% attending university	ns
Engstrom et al.	2003	16	Normal range	6.3	18.8	6.3	ns	37.5
Farley et al.	2009	41	Normal range	FT: 26.8 PT: 26.8	7.3	19.5 ^c	18 high school diploma, 16 received post-secondary education (4 of whom earned associate's degree or technical training certificate, 7 others 1+ bachelor's degrees)	9.8
Gillespie-Lynch et al.	2012	20	Mixed	20.0	35.0	10.0	ns	35.0
Hofvander et al.	2009	122	Normal range	41.0 employed or students	41.0 employed or students	41.0 employed or students	65% graduated upper secondary school, 24% completed college or university studies	59.0

Study	Date	N	IQ	Employed (%)	Supported or sheltered employment (%)	In education (%)	Educational attainment	Not in education and not employed (%)
Howlin et al.	2004	68	Mixed	33.8	20.6	ns	ns	ns
Hutton et al.	2008	135	Mixed	15.6 ^b	ns	ns	ns	ns
Chowdhury et al.	2010	34	Normal range	17.6	11.8	41.2	ns	32.4
Marriage et al.	2009	80	Normal range	ns ^a	ns	ns	ns	ns
Renty & Roeyers	2006	58	Normal range	27.6	18.9	29.3	24.1 college / university, 75.9 attended elementary / high school	24.1
Saldana et al.	2009	74	ns	2.7	18.9 in a work training scheme	21.6	ns	ns
Taylor & Seltzer	2010	242	Mixed	ns	ns	ns	ns	ns
Taylor & Seltzer	2011a	66	Mixed	6.1	12.1	6.1	ns	68.2

NS = not stated. ^a Mean “vocation” scores 1.75-2.78, where 1 = living on disability pension and 5 = employment at full potential. ^b Including supported employment ^c 12.2% full time, 7.3% part time.

successfully completed degree-level study (Cederlund et al., 2008; Eaves & Ho, 2008; Farley et al., 2009; Hofvander et al., 2009; Renty & Roeyers, 2006). Several studies gave examples of employment gained by participants, mostly unskilled positions. Many roles involved repetitive tasks, which might be appropriate for people with ASD who value repetition and sameness, including washing dishes, rolling silverware into napkins, shredding paper and filing. However, some participants had skilled jobs such as cartographer and business manager, or were self-employed (Eaves & Ho, 2008; Engstrom et al., 2003; Gillespie-Lynch et al., 2012; Howlin et al., 2004; Taylor & Seltzer, 2011b).

Inconsistent reporting methods relating to employment and education, and difficulty in establishing rates of employment for individuals with an IQ in the average range or above, limit current understanding of employment and education prospects for adults with ASD. Certainly rates of unemployment are higher than in the general population of most Western countries, even for higher functioning individuals. There was little discussion about how adults might view their employment, and whether they find employment that fulfils their potential and provides a valued role.

Independent living. Thirteen studies report participants' residential status (Table 6). Rates of residential care settings were highest in samples with mixed IQ than samples where no participants had a learning disability, likely reflecting the higher level of basic care support those with learning disability might require. Rates of living with parents were high in all samples, though given many samples focus on early adulthood (highest mean age was 34.9years), this may not be substantially different from general population samples, where young adults might continue to live at home well into their twenties. Rates of independent living are highly varied but

Table 6: Residential status of adults with ASD

Study		N	Male (%)	Age (yrs.) Mean (range)	IQ Mean (range)	Living with parents (%)	Full time residential (%) ^a	Supported living (%) ^a	Living independently (%)
Eaves & Ho	2008	48	77.1	24	Mixed	56.3	0.0	35.4	8.3
Engstrom et al.	2003	16	56.3	31.4 (23-46)	Normal range	37.5	6.3	50.0	6.3
Farley et al.	2009	41	92.7	32.5 (22.3-46.4)	Normal range	56.1	14.6	17.1	12.2
Gillespie-Lynch et al.	2012	20	ns	26.6	Mixed	50.0	35.0	10.0	5.0
Hofvander et al.	2009	122	67.1	Median 29 (16-60)	Normal range	ns	ns	ns	50.0 ^b
Howlin et al.	2004	68	89.7	29.33 (21.16-48.58)	Mixed	38.2	50.0	5.9	4.4
Hutton et al. ^c	2008	135	77.0	34.9 (21-57)	Mixed	c. 25	3.0	c. 60	10.4
Krauss et al.	2005	133	70.7	31.9	Mixed	36.8	ns	63.2 ^d	ns
Renty & Roeyers	2006	58	74.1	28.34 (18-53)	Normal range	55.2	ns	25.9 ^e	18.9 ^f
Saldana et al.	2009	74	85.0	24.6 (18.4-40.1)	ns	87.0	13.5 ^g	8.1 ^h	ns
Shattuck et al. ⁱ	2007	241	75.5	22.0 (10-52)	Mixed	66.4	9.9	22.0	1.7
Taylor & Seltzer ⁱ	2010	242	73.0	16.3 (10.1-23.5) ^j	Mixed	80.6	ns	ns	ns
Taylor & Seltzer ⁱ	2011a	170	76.0	16.7 (11.3-21.9) ^j	Mixed	82.4	ns	ns	ns

^a In some cases it is difficult to distinguish between these categories. Where information is available, this review considers any residence with full-time staff as a residential setting, and any with some staff support as supported living ^b Of subjects over 23, plus 'some' of the younger participants ^c Circa (c.) values are given when no precise data is reported ^d 63.2% reside in a 'non-family setting' ^e Supported or residential living (not reported separately) ^f Including 8.6% living with a partner ^g Reported as receiving support with residence ^h Reported as receiving 'home support' ⁱ Related samples ^j Age at the beginning of prospective study. Data is reported from 10yr follow up. ns = not stated

low across most samples. High levels of variation might be influenced by sampling biases, dependent on recruitment methods and sample characteristics (e.g. age, adaptive living skills).

Most studies reported residential status as a descriptive of participant demographics, with limited details. It is particularly difficult to assess levels of support given in “supported living” arrangements. There is little discussion of aspired residential status, and the implicit assumption of most studies is that independent living is the favoured outcome. One study did ask mothers open-ended questions about the pros and cons of their child’s residential status (Krauss, Seltzer, & Jacobson, 2005) and interestingly found that the adult child with ASD living at home was reported to have had greatest benefits for the family, and living independently had greatest benefits for the person with ASD themselves. This highlights conflicting needs and interests within families, the importance of adulthood outcomes for family systems, and potential confounds of using parental report about an adult child’s wishes.

Farley et al. (2009) and Gillespie-Lynch et al. (2012) additionally report adaptive living skills results from the Vineland Adaptive Behaviour Scales (Sparrow, Balla, & Cicchetti, 1984), which include three scales; daily living, communication and socialisation. These longitudinal studies report improvements in daily living skills over time, but not in the other scales. One possible explanation for this is that communication and socialisation difficulties form part of the core deficits in ASD, whereas daily living is not inherently impaired for this group.

In a measure of independence based on information from clinical notes, Marriage et al. (2009) rated participants’ independence on a scale of one (poor functioning) to five (age-appropriate attainment). They found a mean score of three

in a group of adults with ASD and normal range IQ, indicating on-going deficits in adulthood daily independent functioning and skills. Improvements in skills may also slow more into adulthood for those without a comorbid learning disability (Taylor & Seltzer, 2010). This may interact with findings that young adults with ASD without learning disability were three times more likely to have no daily activities than those with a learning disability (Taylor & Seltzer, 2011b). For this group, impairments may not be severe enough to meet eligibility criteria for support services that could help them to find appropriate activities and to continue to improve their skills in adulthood.

Mental health. Nine studies report mental health outcomes for adults with ASD (Table 7). Prevalence reports of mental health problems are highly varied, ranging from 22% (Hutton et al., 2008) to Hofvander et al.'s (2009) finding that 100% of Asperger Syndrome and PDD-NOS groups and 80% of an autistic disorder group had a mental health problem. Part of the explanation for these discrepancies may be methodological differences. Some studies report outcomes from questionnaire measures (e.g. Lai et al., 2011), which might be over-inclusive and lacking in specificity in comparison to more comprehensive assessments such as psychiatric examinations and structured interviews (e.g. Billstedt et al., 2005; Hofvander et al., 2009).

Several studies consider the nature of mental health difficulties. Rates of mood disorder are consistently high, as are rates of anxiety. The studies reviewed here suggest rates of anxiety and in particular obsessive compulsive disorder (OCD) to be up to 50% (Eaves & Ho, 2008; Hofvander et al., 2009), with lower rates of bipolar disorder (2-10%) (Farley et al., 2009; Taylor & Seltzer, 2011a) and psychosis (2-12%) (Farley et al., 2009; Hofvander et al., 2009). Despite high variation in

Table 7. Mental health problems in adults with ASD

Study	N	IQ	Method of assessing mental health	Any mental health problem (%)	Depression MDD Mood disorder (%)	Psychosis (%)	OCD (%)	GAD (%)	Anxiety (%)	Bipolar (%)	
Billstedt et al.	2005 ^a	120	Mixed	Psychiatric examination	ns	1	7 ^b	ns	ns	ns	ns
Cederlund et al.	2008 ^a	140	Mixed	Diagnoses from independent psychiatrists	ns	ns	5	ns	ns	ns	ns
Eaves & Ho	2008	48	Mixed	Telephone interview (informant)	77	21	ns	50	ns	50	6
Farley et al.	2009	41	Normal range	ns	59	42 ^c	2	7	ns	22	2
Hofvander et al.	2009	122	Normal range	SCID-I or DSM-IV interview	80 100	53	12	24	ns	50	ns
Hutton et al.	2008 ^d	135	Mixed	SAPPA informant interview	22 ^c	ns	ns	ns	ns	ns	ns
Lai et al.	2011	62	Normal range	BAI, BDI and OCI-R questionnaires	70 ^f	ns	ns	ns	ns	ns	ns
Marriage et al. ^g	2009	33	Normal range: ASD diagnosed pre-18	Mental status exam	79	24	6	15	ns	27	ns
		34	Normal range: ASD diagnosed post-18	Mental status exam	80	44	5	0	ns	23	ns

Study	N	IQ	Method of assessing mental health	Any mental health problem (%)	Depression MDD Mood disorder (%)	Psychosis (%)	OCD (%)	GAD (%)	Anxiety (%)	Bipolar (%)	
Taylor & Seltzer	2011a	66	Mixed	Parents asked about psychiatric history	ns	8	0	23	ns	24	10

^a Articles report findings from related samples. ^b Includes diagnoses of bipolar disorder. ^c Includes 10% with suspected but unconfirmed diagnosis. ^d Only reports new onset problems (i.e. difficulties were not present at the time when participant was originally referred to ASD clinic). ^e Includes 16% with diagnoses and 6% with dubious/uncertain difficulties. ^f Scored in clinically significant range in questionnaire measures. ^g Reported results do not include participants with ID.

prevalence estimates, reports of elevated risk of mental health difficulties are certainly consistent enough among the studies to conclude that adults with ASD are at risk of mental health difficulties. Notably, one of the studies reporting the highest prevalence rates for mental health problems was one of those with a high quality rating on the adapted NOS (Hofvander et al., 2009). These findings are particularly significant as people with ASD may find it difficult to access and benefit from mental health treatment. Given that UK policy encourages inclusion of people with additional needs in mainstream mental health services, this issue requires consideration beyond specialist ASD service provision.

Cognitive ability. Six studies report intellect data beyond screening for IQ-related inclusion criteria (Billstedt et al., 2005; Cederlund et al., 2008; Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2004; Lai et al., 2011). Two of these report adulthood IQ scores to profile their sample, without pre-scores (Howlin et al., 2004; Lai et al., 2011). Of the other four studies, two related prospective follow-up studies (i.e. samples are subgroups of the same larger sample, which may overlap) report a downward shift in IQ scores as participants reach adulthood (Billstedt et al., 2005; Cederlund et al., 2008). However, this was largely amongst participants with lower IQ to begin with (which may be difficult to measure accurately) and data was often based on estimates from the Vineland Adaptive Behaviour Scales (Sparrow et al., 1984), rather than more comprehensive cognitive assessments used with other participants. Eaves and Ho (2008) found slightly fewer of their sample had an IQ above 50 in adolescence than before, but do not report significance testing of this change or IQ in their adulthood follow up. Further, Farley et al. (2009) followed up 30 adults from their sample at a mean age of 32.5 (range 22.3-46.4), and compared current IQ scores to childhood assessments of cognitive ability (mainly obtained

during clinical assessments). They found similar scores (83.68 and 88.93) in their mixed ability sample, suggesting stable intellectual functioning. The reviewed studies did not consider other cognitive outcomes.

Quality of life. Three of the studies reviewed report measures of quality of life (Eaves & Ho, 2008; Renty & Roeyers, 2006; Saldana et al., 2009). Saldana et al. (2009) use the ComQol questionnaire (Cummins, 1997), asking family members to rate importance and satisfaction in relation to seven life domains; material wellbeing; health; productivity; intimacy; safety; place in community; emotional wellbeing. Whilst the informants knew participants well and thus represent an appropriate proxy respondent, the researchers dropped the emotional wellbeing item as the constituent rating of “overall happiness” was too difficult for informants to answer, and only 25 were able to respond to five or more (of seven) items in the questionnaire. This suggests that even close relatives find quality of life assessment challenging for this group. The authors found that informants believed material wellbeing and intimacy within the family were important in quality of life.

In a similar approach, Eaves and Ho (2008) used informant-based quality of life assessments, asking parents to rate their satisfaction with various areas of their child’s life; healthcare; community support; government support; working life; education. Satisfaction was highest in healthcare (65% satisfied or very satisfied) and lowest in education (42% satisfied or very satisfied). A key difficulty in comparing the outcomes of these studies is that the two measures include different domains, highlighting a lack of conceptual clarity around “quality of life”. Further, a difficulty with informant-based measures is the risk of assessing informant priorities rather than participants’ quality of life. It is preferable to obtain self-ratings where this is feasible and the findings likely to be valid.

In a study reported by Renty and Roeyers (2006), high-functioning adults with ASD completed the Quality of Life Questionnaire, administered in an interview format. This questionnaire has subscales for satisfaction, competency/productivity, empowerment/independence and social belonging/community integration, and different scales to the informant-based quality of life measures. They found participants were able to complete the questionnaires, and that the biggest influences on quality of life ratings were perceived (not actual) level of informal support available, and the discrepancy between needed and perceived formal support. Although this was reported seven years ago, this review has found little evidence of researchers continuing to attempt self-report ratings around subjective outcomes and quality of life.

Direct comparisons between these studies are limited by differences in measures used, as there is no agreed concept of “quality of life”. These few studies do show however, that it is feasible to ask higher functioning people with ASD their own priorities and needs. The studies reviewed highlighted different priorities in terms of quality of life. This is likely to be attributable to asking different questions, and shows that there is currently an extremely limited understanding of adulthood quality of life for people with ASD. It is not clear how appropriate informant measures of quality of life are in this client group, an issue that could be addressed by further empirical research comparing self- and informant-report measures for individuals able to self-report.

Discussion

The studies reviewed consistently reported on-going difficulties for adults with ASD in a range of areas. Adults diagnosed with ASD in childhood reliably continued to meet ASD diagnostic criteria in at least some measures in adulthood although sub-

divisions within ASD diagnostic criteria (e.g. atypical autism) were changeable. This echoes previous findings in this area (Lord et al., 2012) and offers support to recent changes to DSM-5 that have removed these diagnostic definitions (American Psychiatric Association, 2013).

Many of the reviewed studies consider outcomes related to the core ASD phenotype, including atypicalities in social interaction, communication and RSBs. The evidence suggests that adults with ASD may be vulnerable to social isolation and victimisation in adulthood. Whilst some of the strongest studies of RSBs did not report data for participants with and without learning disability separately, there was some indication that more subtle manifestations of RSBs, such as fixated interests, might be persistent in higher functioning individuals with ASD. Fixated interests were less widely reported, however, than more easily observable repetitive behaviours and so this remains inconclusive. On-going differences in social communication were evident, although verbal skills may improve into adulthood. This may be because some aspects of communication, such as gestures and facial expressions are more subtle than spoken language, which may make them more difficult to learn over time. Social imagination deficits were less commonly studied and there were no studies of change over time, but the reports available suggest impairment is common in adulthood.

Studies of core ASD characteristics suggest an interesting yet inconclusive picture about how difficulties may change over time. Impairments may become less obvious as RSB characteristics become more subtle and verbal skills improve, though difficulties continue to cause significant impairment. This may contribute to a risk of assessment measures being less sensitive to adult ASD features, which may explain low scores (indicating less impairment) of ASD adults on behavioural

observation measures such as the ADOS-G (e.g. Lai et al., 2011), highlighting the importance of comprehensive clinical assessment and a thorough developmental history.

Studies of other psychosocial outcomes report on-going difficulties in a range of areas, consistent with previous reviews (e.g. Howlin & Moss, 2012). Variable rates of employment and education were reported, though unemployment rates were consistently high. Rates of independent living were low, though often housing data was only reported as part of the sample description and so was not rigorous. Scores on adaptive living skills measures were reported as higher than communication and social skills (possibly as these difficulties form key ASD features) though were consistently below age-appropriate attainment. This level of difficulty may cause significant impairment but leave higher functioning adults with ASD below the threshold for service involvement. Notably, it is often reported that those without a learning disability have more unmet needs in adulthood (e.g. Taylor & Seltzer, 2010, 2011a). Rates of mental health problems were elevated in several studies, particularly mood disorders and anxiety. One study highlighted concerning high rates of suicidal ideation (Shtayermman, 2008), although this finding was not replicated in the reviewed studies. There were few references to behavioural comorbidities that are commonly reported in children with ASD (e.g. Mayes et al., 2012). This could suggest that there is a lower prevalence of behavioural difficulties in adults with ASD, that the relationship between ASD and behavioural difficulties is mediated by the presence of a learning disability (and therefore not highlighted in this review of studies of higher functioning individuals) or that there is a sampling or reporting bias within the reviewed studies.

There was very little investigation of participants' own views, aspirations or priorities in adulthood, as most reviewed studies relied on caregiver report or objective measures. The only studies to consider participants' subjective experience in a meaningful way were those using quality of life measures. These were usually informant-report questionnaire measures, however. This is despite a move in a range of clinical specialities, including learning disabilities (Department of Health, 2010), towards a focus on person-centred care and outcomes. One example of how this might be relevant is that almost all of the reviewed studies report data collected in Western cultures where independence in adulthood is valued. Independent living might, for example, be considered less of a priority in collectivist cultures. As few studies to date have focused on participants' own valued outcomes, the feasibility of research in this area has not been established. None of the reviewed studies report unsuccessful attempts to ask about valued outcomes, though there may be a publication bias against unsuccessful interview methods. As many adults with ASD and an IQ in the normal range have adequate or even superior verbal skills, interviewing them about their own views and aspirations seems realistic.

The limitations of this review should be kept in mind when considering the findings. Centrally, the area of "outcomes" has poor conceptual clarity. The search terms used were deliberately broad to include a number of different types of outcome, but the lack of a consistent way to define outcomes makes comprehensive literature searching a challenge. Further, many of the included studies report data from samples with mixed IQ scores, individuals within these samples may have very different outcomes, making it difficult to distinguish the impact of ASD from learning disability. The studies included in this review have selected samples based on diagnostic criteria that may become redundant with the publication of DSM-5

(American Psychiatric Association, 2013), and some preliminary studies suggest that 22-39 percent of people diagnosed with ASD under previous criteria may no longer meet diagnostic thresholds (McPartland, Reichow, & Volkmar, 2012; Wilson et al., 2013). Therefore, a significant minority of the individuals included in the reviewed studies may not meet new ASD criteria. The impact of this on understanding ASD-specific outcomes will not be known until the new criteria have been in use for some time. However, a strength of this review is that studies limited in methodological quality or relevance were systematically excluded, protecting the quality of the data reviewed. The review included prospective follow up studies of large samples over multiple time points, and most studies used validated measures, particularly in assessing ASD symptoms. However, there remains significant variation in methodological strength across the reviewed studies. Methodologically weaker studies, including those with smaller sample sizes and less comprehensive assessments of outcome have been given less weight in this review.

This review included both longitudinal and cross-sectional research in an attempt to be comprehensive in reviewing what is known about ASD in adulthood. As cross-sectional adult samples are often recruited from clinical services, this may exclude those who do not require on-going support, thus underestimating those who manage independently or with only family support in adulthood. Notably, the longitudinal analyses highlighted the positive progress made by some participants in some areas, such as improvement in communication skills over time (Gillespie-Lynch et al., 2012; Shattuck et al., 2007; Taylor & Seltzer, 2010), whereas cross-sectional studies cited positive outcomes less frequently.

The findings reported here have a number of clinical implications. They suggest restricted and repetitive behaviours may manifest in subtle ways for some

adults with ASD, highlighting the importance of comprehensive assessment when adults present for ASD assessment. The high comorbid rates of mental health problems suggest a need for clinicians in ASD services to be aware of mental health, but also for mental health services to be aware that clients on their caseload may have ASD. Perceived social support is identified as important in quality of life, and so clinicians should be careful to consider helping adults with ASD develop their social networks. Importantly, this might mean identifying sources of social support for when needed, and not necessarily working to develop reciprocal friendships if the person does not desire them.

This review highlights some of the gaps in available research. Little is known about the perspectives of adults with ASD on adulthood outcomes and aspirations. To our knowledge, there is no validated measure or model for assessing aspirations outcomes specifically for people with ASD in adulthood. Such approaches would be helpful for intervention and outcome research, as well as clinical practice. Focusing on aspirations and valued outcomes in addition to support needs could promote more person-centred approaches to care, and could highlight the skills adults with ASD have to offer, as well as the support needs they may have.

References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental health disorders* (4th ed.). Washington DC: APA.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a

- population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531), 210–215.
- Baron-Cohen, S., & Hammer, J. (1997). Is autism an extreme form of the male brain? *Advances in Infancy Research*, 11, 193–217.
- Baron-Cohen, S., Richler, J., Bisarya, D., Gurunathan, N., & Wheelwright, S. (2003). The systemizing quotient: an investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 358(1430), 361–374. doi:10.1098/rstb.2002.1206
- Baron-Cohen, S., & Wheelwright, S. (2003). The Friendship Questionnaire: an investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Journal of Autism and Developmental Disorders*, 33(5), 509–517.
- Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The “Reading the Mind in the Eyes” Test revised version: a study with normal adults, and adults with Asperger syndrome or high-functioning autism. *Journal of Child Psychology and Psychiatry*, 42, 241–251.
- Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self*. New York: The Free Press.
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35(3), 351–360. doi:10.1007/s10803-005-3302-5
- Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: a comparative longitudinal follow-up study

- more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders*, 38(1), 72–85. doi:10.1007/s10803-007-0364-6
- Chowdhury, M., Benson, B. A., & Hillier, A. (2010). Changes in restricted repetitive behaviors with age: a study of high-functioning adults with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4(2), 210–216. doi:10.1016/j.rasd.2009.09.006
- Cummins, R. (1997). *Comprehensive Quality of Life Questionnaire - Intellectual Disability*. Deakin University.
- Department of Health. (2010). Personalisation through person-centred planning. Department of Health. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115249.pdf
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(4), 739–747. doi:10.1007/s10803-007-0441-x
- Engstrom, I., Ekstrom, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*, 7(1), 99–110. doi:10.1177/1362361303007001008
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., Block, H., Pingree, C.B., Ritvo, E. R., Ritvo, R. A., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2(2), 109–118. doi:10.1002/aur.69

- Gillberg, I. C., & Gillberg, C. (1989). Asperger syndrome - some epidemiological considerations: a research note. *Journal of Child Psychology and Psychiatry*, 30, 631–638.
- Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders*, 42(2), 161–174. doi:10.1007/s10803-011-1222-0
- Henninger, N. A., & Taylor, J. L. (2012). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. Retrieved from <http://aut.sagepub.com/content/early/2012/08/16/1362361312441266.abstract>
- Hofvander, B., Delorme, R., Chaste, P., Nyden, A., Wentz, E., Stahlberg, O., Herbrecht, E., Stopin, A., Anckarsater, H., Gillberg, C., Rastam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9(1), 35. doi:10.1186/1471-244X-9-35
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212–229.
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57(5), 275–283.
- Hutton, J., Goode, S., Murphy, M., Le Couteur, A., & Rutter, M. (2008). New-onset psychiatric disorders in individuals with autism. *Autism*, 12(4), 373–390. doi:10.1177/1362361308091650
- Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential

status. *Journal of Intellectual Disability Research*, 49(2), 111–124.

doi:10.1111/j.1365-2788.2004.00599.x

- Lahaie, A., Mottron, L., Arguin, M., Berthiaume, C., Jemel, B., & Saumier, D. (2006). Face perception in high-functioning autistic adults: evidence for superior processing of face parts, not for a configural face-processing deficit. *Neuropsychology*, 20(1), 30–41. doi:10.1037/0894-4105.20.1.30
- Lai, M-C., Lombardo, M. V., Pasco, G., Ruigrok, A. N. V., Wheelwright, S. J., Sadek, S. A., Chakrabarti, B., MRC AIMS Consortium, & Baron-Cohen, S. (2011). A Behavioral Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions. (J. G. Scott, Ed.) *PLoS ONE*, 6(6), e20835. doi:10.1371/journal.pone.0020835
- Lord, C., Petkora, E., Hus, V., Gan, W., Lu, F., Martin, D., Ousley, O., Guy, L., Bernier, R., Gerts, J., Algermissen, M., Whitaker, A., Sutcliffe, J., Warren, Z., Kiln, A., Saulnier, C., Hanson, E., Hundley, R., Piggot, J., Fombonne, E., Steiman, M., Miles, J., Kanne, S., Goin-Kochel, R., Peters, S., Cook, E., Guter, S., Tjernagel, J., Green-Snyder, L., Bishop, S., Esler, A., Gotham, K., Luyster, R., Miller, F., Olson, J., Richler, J., & Risi, S. (2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry*, 69(3), 306. doi:10.1001/archgenpsychiatry.2011.148
- Lord, C., Risi, S., Lambrecht, L., Cook, E., Leventhal, B., DiLavore, P., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule - Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223.

- Lord, C., Rutter, M., & LeCouteur, A. (1994). Autism Diagnostic Interview - Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659–685.
- Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism spectrum disorder grown up: a chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(4), 322–328.
- Mayes, S. D., Calhoun, S. L., Aggarwal, R., Baker, C., Mathapati, S., Anderson, R., & Petersen, C. (2012). Explosive, oppositional, and aggressive behavior in children with autism compared to other clinical disorders and typical children. *Research in Autism Spectrum Disorders*, 6(1), 1–10.
doi:10.1016/j.rasd.2011.08.001
- Mazefsky, C. A., Folstein, S. E., & Lainhart, J. E. (2008). Overrepresentation of mood and anxiety disorders in adults with autism and their first-degree relatives: what does it mean? *Autism Research*, 1(3), 193–197.
doi:10.1002/aur.23
- McCabe, H., & Wu, S. (2009). Helping each other, helping ourselves: a case of employment for an adult with autism in Nanjing, China. *Journal of Vocational Rehabilitation*, 30, 57–66. doi:10.3233/JVR-2009-0453
- McPartland, J., Reichow, B., & Volkmar, F. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4).
- Munesue, T., Ono, Y., Mutoh, K., Shimoda, K., Nakatani, H., & Kikuchi, M. (2008). High prevalence of bipolar disorder comorbidity in adolescents and young adults with high-functioning autism spectrum disorder: a preliminary study of

44 outpatients. *Journal of Affective Disorders*, 111(2-3), 170–175.

doi:10.1016/j.jad.2008.02.015

Nishimura, M., Rutherford, M. D., & Maurer, D. (2008). Converging evidence of configural processing of faces in high-functioning adults with autism spectrum disorders. *Visual Cognition*, 16(7), 859–891. doi:10.1080/13506280701538514

Orsmond, G., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, 34(3), 245–256.

Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. *Autism*, 10(5), 511–524. doi:10.1177/1362361306066604

Saldana, D., Alvarez, R. M., Lobaton, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009). Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. *Autism*, 13(3), 303–316. doi:10.1177/1362361309103792

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1735–1747. doi:10.1007/s10803-006-0307-7

Shtayermman, O. (2008). Suicidal ideation and comorbid disorders in adolescents and young adults diagnosed with Asperger's syndrome: a population at risk. *Journal of Human Behavior in the Social Environment*, 18(3), 301–328. doi:10.1080/10911350802427548

- Shtayermman, O. (2009). An exploratory study of the stigma associated with a diagnosis of Asperger's syndrome: the mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. *Journal of Human Behavior in the Social Environment*, 19(3), 298–313. doi:10.1080/10911350902790720
- Smith, L., Greenberg, J., Seltzer, M. M., & Hong, J. (2008). Symptoms and behavior problems of adolescents and adults with autism: effects of mother–child relationship quality, warmth, and praise. *American Journal on Retardation*, 113(5), 387–402. doi:10.1352/2008.113:387–402
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). *Vineland adaptive behavior scales*. Circle Pines, MN: American Guidance Service.
- Taylor, E., Target, M., & Charman, T. (2008). Attachment in adults with high-functioning autism. *Attachment & Human Development*, 10(2), 143–163. doi:10.1080/14616730802113687
- Taylor, J., & Seltzer, M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40(12), 1431–1446. doi:10.1007/s10803-010-1005-z
- Taylor, J., & Seltzer, M. (2011a). Changes in the mother–child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(10), 1397–1410. doi:10.1007/s10803-010-1166-9
- Taylor, J., & Seltzer, M. (2011b). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566–574. doi:10.1007/s10803-010-1070-3

- Vlamings, P. H. J. M., Stauder, J. E. A., Son, I. A. M., & Motttron, L. (2005). Atypical visual orienting to gaze- and arrow-cues in adults with high functioning autism. *Journal of Autism and Developmental Disorders*, 35(3), 267–277. doi:10.1007/s10803-005-3289-y
- Wells, G., Shea, B., O’Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2004). *The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses*. Ottawa Health Research Institute. Retrieved from [http://www.medicine.mcgill.ca/rtamblyn/Readings%5CThe%20Newcastle%20-%20Scale%20for%20assessing%20the%20quality%20of%20nonrandomise d %20studies%20in%20meta-analyses.pdf](http://www.medicine.mcgill.ca/rtamblyn/Readings%5CThe%20Newcastle%20-%20Scale%20for%20assessing%20the%20quality%20of%20nonrandomise%20studies%20in%20meta-analyses.pdf)
- Whitehouse, A. J. O., Watt, H. J., Line, E. A., & Bishop, D. V. M. (2009). Adult psychosocial outcomes of children with specific language impairment, pragmatic language impairment and autism. *International Journal of Language & Communication Disorders*, 44(4), 511–528. doi:10.1080/13682820802708098
- Wilson, C. E., Gillan, N., Spain, D., Robertson, D., Roberts, G., Murphy, C. M., Maltezos, S., Zinkstok, J., Johnston, K., Dardani, C., Ohlsen, C., Deely, P. Q., Craig, M., Mendez, M. A., Happe, F., Murphy, D. G. M. (2013). Comparison of ICD-10R, DSM-IV-TR and DSM-5 in an adult autism spectrum disorder diagnostic clinic. *Journal of Autism and Developmental Disorders*, (Online). doi:10.1007/s10803-013-1799-6
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11–29.

- Wing, L., Gould, J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-V: better or worse than the DSM-IV? *Research in Developmental Disabilities, 32*(2), 768–773. doi:10.1016/j.ridd.2010.11.003
- Wing, L., Leekham, S., Libby, S., Gould, J., & Larcombe, M. (2002). The Diagnostic Interview for Social and Communication disorders: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry, 43*, 307–325.
- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8*(3), 151–161. doi:10.1002/mrdd.10029
- Yamamoto, Y., & Nihei, Y. (2008). Difficulties in adjusting to college life experienced by students with pervasive developmental disorders: comparison with schizophrenic students. *Tohoku Psychologica Folia, 67*, 1–5.

Part 2: Empirical Paper

Aspirations and outcomes of people with autism spectrum disorders in emerging
adulthood

Abstract

Aims

This study explored subjective experiences of young adults with ASD, and their parents, to understand their perspectives on adulthood outcomes, their aspirations and their concerns for the future.

Method

Seven young adults with ASD and without a learning disability and thirteen parents took part in semi-structured interviews. A phenomenological approach was taken to explore experiences of being or parenting a young adult with ASD.

Participants were also asked about their aspirations for the future for themselves or their child, and possible barriers to reaching personal goals. Interview transcripts were analysed using framework analysis.

Results

Young adults with ASD described wide-ranging interests, skills and aspirations, beyond those often reported in the literature. There was substantial variation in levels of independence, health and wellbeing, social contact and daily activity. Parents identified significant challenges facing their children in the future, particularly in the areas of interpersonal interactions and independent living skills. Key themes raised related to current outcomes, aspirations and potential barriers are conceptualised in a proposed framework for understanding and assessing the outcomes and aspirations of adults with ASD.

Conclusions

Whilst young adults with ASD face significant challenges, this study finds more varied outcomes than previous research suggests.

Aspirations and outcomes for people with autism spectrum disorders in emerging adulthood

Introduction

Although approximately half of individuals with autism spectrum disorders (ASD) have a comorbid learning disability (e.g. Baird et al., 2006), ASD occurs across the spectrum of intellectual ability. The impact of ASD varies between individuals, and some individuals with ASD are able to live independently, have successful relationships and careers. Media reports speculate that famous historical figures successful in the arts and sciences may have had autism spectrum conditions, including Mozart, Sir Isaac Newton and Lewis Carroll (Armstrong, 2011). However, the research literature suggests that positive outcomes are not the norm, and many people with ASD both with and without learning disabilities can expect poor outcomes; few are reported to achieve independent living, close friendships or employment, and adults with ASD are at increased risk of mental health problems (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004; Howlin & Moss, 2012; Taylor & Seltzer, 2010, 2011).

One of the difficulties of assessing outcomes for adults with ASD is that despite an increasing volume of research in this area, little attention has been paid to the subjectively valued outcomes of people with ASD (Henninger & Taylor, 2012; see also Part 1 of this thesis). In a review of how outcomes for adults with ASD have been conceptualised, Henninger and Taylor (2012) identify three distinct “eras” in ASD outcome research, beginning with vague ratings of “good” to “very poor” before the early 2000s, moving to more reliable ordinal rating scales based on Howlin et al.’s (2004) work and more recently to researchers beginning to think

about outcomes more closely related to the subjective experience of people with ASD. They argue that balancing the criteria based on objective societal norms with subjective perspectives will move towards a more “complete and multidimensional” picture of adult outcomes, which will have greater validity.

More comprehensive concepts of outcome that include subjectively meaningful measures have become increasingly prominent in other specialties. For example, there has been recognition of the importance of people’s aspirations and values among those working in learning disabilities (e.g. Aspirations For Life, 2012; Department of Health, 2010) and early intervention in psychosis (IRIS, 2012) services. ASD research lags behind in this area, despite guidance for clinical practice highlighting the importance of fostering autonomy and working in partnership with adults with autism, and clearly stating that support and care should take into account people’s needs and preferences (NICE, 2012). In order to promote best practice and to understand and meet the evolving needs and expectations of service users, clinicians and researchers must take steps towards incorporating the aspirations and values of young people with ASD at the centre of research and clinical practice.

In typical development, a key period for the formation and pursuit of personal values and aspirations is the period between adolescence and adulthood, conceptualised by Arnett (2000, 2007) as “emerging adulthood.” Arnett describes this as a period occurring between late teens and mid-late twenties, characterised by a great variability in demographic status; an overwhelming majority of adolescents live with caregivers and are in education, and a similar majority of thirty year olds live independently. Between these ages, however, there are no longer clear norms in modern western society (Arnett, 2000). The uncertainty, decisions and transitions associated with the emerging adulthood period might present particular challenges

for individuals with ASD, who have been recognised since the earliest conceptualisations of autism to find transition and change difficult.

The current study aimed to expand the limited evidence base on subjective outcomes for young adults with ASD, with a focus on people in the “emerging adulthood” age range and without comorbid learning disability. To do so, it was necessary to take a more phenomenological approach than the more commonly reported quantitative and categorical outcome studies. Therefore, a qualitative interview method was adopted. To date, few studies have asked young adults with ASD about their own perspectives on their current and future activities and plans; even the quality of life outcome studies reviewed in Part 1 of this thesis often used parent-report measures (Eaves & Ho, 2008; Saldana et al., 2009). The current study presented an opportunity to assess the feasibility of doing so and to move towards involving young adults more meaningfully in outcomes research. It also had the potential to inform approaches to working with people with ASD to support them in reaching their personally valued outcomes in adulthood.

As parents were expected to be providing significant support to some young adults with ASD, interviews were conducted with young adults with ASD and also their parents. It was anticipated that parents might be uniquely positioned to offer insight into their child’s experiences, particularly if their child’s communication difficulties impacted on their ability to discuss their experiences. Parents might also be able to share important experiences of their own. Therefore, the study was also designed to explore similarities and differences in parental views on current and aspired outcomes for their young adult children.

Specifically, this study used semi-structured qualitative interviews with both young adults with ASD and their parents to address three research questions:

1. What are the views of young adults with ASD and their parents on their current circumstances and activities?
2. To what outcomes do young adults with ASD and their parents aspire for themselves (or their child) in adulthood?
3. What barriers do young adults with ASD and their parents experience or anticipate in achieving aspired outcomes?

Additionally, the study aimed to incorporate the evidence gathered into a conceptual framework for working with young adults with ASD in a way that supports them in achieving their own aspirations.

Method

Overview

Children diagnosed with ASD, and their parents, were contacted in early adulthood and invited to complete one-off semi-structured qualitative interviews. The interviews comprised questions exploring aspirations for adulthood for themselves (or their child), barriers to achieving those aspirations and their experiences of being (or parenting) a young adult with ASD.

Service-user consultation

During the design stage of this study, a young adult who had received an ASD diagnosis in childhood contacted the department and expressed an interest in being involved in research. She volunteered to become a consultant to the study, and contributed to study design, information sheets, consent forms and measure development.

Context

Participants were recruited from a Tier 4 NHS service providing ASD assessments for children aged between four and seventeen, where local services had

not been able to provide or agree on diagnosis. Young adults in this study received ASD diagnoses at the clinic between 2001 and 2005. At this time, local services were not well-developed in the UK, and not all local services offered comprehensive ASD assessments, particularly in cases of high-functioning individuals. Children receiving diagnoses at the clinic were usually referred back to local services for follow-up care, and so the clinic had not been in contact with the families involved in this study for a number of years.

Participants

Twenty-one individuals from eleven families took part in the study, including seven young adults with ASD, eleven mothers and two fathers. One person (a mother) was excluded as there was doubt over the validity of her son's ASD diagnosis, and she did not consider him to have ASD. Young adults included six males and one female, with a mean age of 20.6 years (SD 1.6, range 18-22) at the time of interview. The mean age of children of all the families, including those where young adults declined to take part was 21.5 years (SD 2.0, range 18-24). Diagnoses were received at the clinic 7.7-12.7 years ago (mean 9.6 years, SD 1.8) at a mean age of 12.0 years (SD 2.7, range 8-16) (Table 1).

Ethical approval

Ethical approval for this study was granted by the NRES Committee North West - Preston (Ref 12/NW/0073) (Appendices 03 and 04).

Recruitment procedure

Records of children assessed between March 1999 and June 2007 were reviewed. Families were eligible for the study if they met three initial criteria:

Table 1: Participant details

Family ^a	Parent took part	YP took part	YP gender	YP Age at interview	YP age at clinical assessment	Estimated IQ ^b (VIQ/PIQ)	Living	Employment	Statement	Highest qualification	Support	Other diagnoses
1	M	N	F	22.23	10.93	- ^c	With parents	Volunteer	Yes	Level 1	None	OCD
2	M+F	Y	M	22.35	14.57	91 / 60	With parents	Unemployed	Yes	NVQ Level 2	Preparation for Work Course	Arthritis
3	M	Y	F	21.13	8.42	117 / 99	Private rented	Unemployed	No	GCSE	None	Depression Arthritis
4	M	Y	M	18.93	10.75	79 / 77	With parents	Student	Yes	BTEC Level 2	Weekly meetings (learning mentor)	None
5	M	N	M	24.35	13.14	- ^c	With family members	Unemployed	Yes	City & Guilds qualification	None	ADHD Social Conduct Disorder
6	M	N	M	24.31	16.30	- ^c	Supported accommodation	Unemployed	Yes	None	Weekly meetings (voluntary org.)	DAMP
7	M+F	Y	M	19.29	9.57	91 / 89	With parents	Student	Yes	AS Level	Extra support at college	None
8	Excluded	-	-	-	-	-	-	-	-	-	-	-
9	M+F	Y	M	22.87	15.08	86 / 75	With parents	PT Shelf stacker	No	GCSE	None	None
10	M	Y	M	20.54	11.97	100 / 103	With parents	Student (BTEC)	Yes	BTEC Level 2	Social Services	None
11	M	Y	M	19.44	9.04	122 / 105	Independent (uni halls)	Student (undergrad.)	No	A Level	None	None

M=mother F=father PT=part time FT=full time VIQ=Verbal IQ PIQ=Performance IQ. ^aTo preserve confidentiality between family members taking part in this study, quotes in this report are not linked with these family identification numbers. ^bAt time of childhood assessment. ^cYoung person did not take part, therefore HADS not completed and no consent to access clinical records was given

1. Met criteria for a diagnosis of ASD based on the Autism Diagnostic Observation Schedule (ADOS-G) (Lord et al., 2000) at the time of clinic assessment
2. IQ score or IQ estimate reported at 70 or above, i.e. in the “normal” or “average” range or above at the time of clinic assessment
3. Young person aged between 18-30 years old on 14th June 2012, i.e. in the “emerging adulthood” period at the time of the study

One hundred and thirty three young people met these criteria. Five files were missing basic details and so were excluded, leaving 128 eligible young adults (111 males, 17 females). Given the much higher frequency of males, the sampling strategy was stratified to over-include females. Therefore, records of all of the females, sixty-three randomly selected males, and the parent or guardian(s) who brought them to the clinic were then requested from an electronic record keeping system. Of these eighty records requested, electronic versions of sixty-six records were available. Of these sixty-six, thirty-three had been given a clinical diagnosis of ASD as a result of their assessment and resided within a two-hour journey time of London. Five were excluded due to reasons of severe complexity, risk or child protection concerns at the time of the assessment (Fig. 1).

The remaining twenty eight families were then contacted by post (Appendices 05 and 06) and invited to take part. This letter was followed by a phone call two weeks later. Where telephone contact details were out of date, a second letter was sent to the address held on file explaining that the researchers were unable to contact them and inviting them to make contact. Fifteen of the twenty eight families (53.6%) were contactable. Four families declined to take part (14.3%), and eleven were recruited into the study.

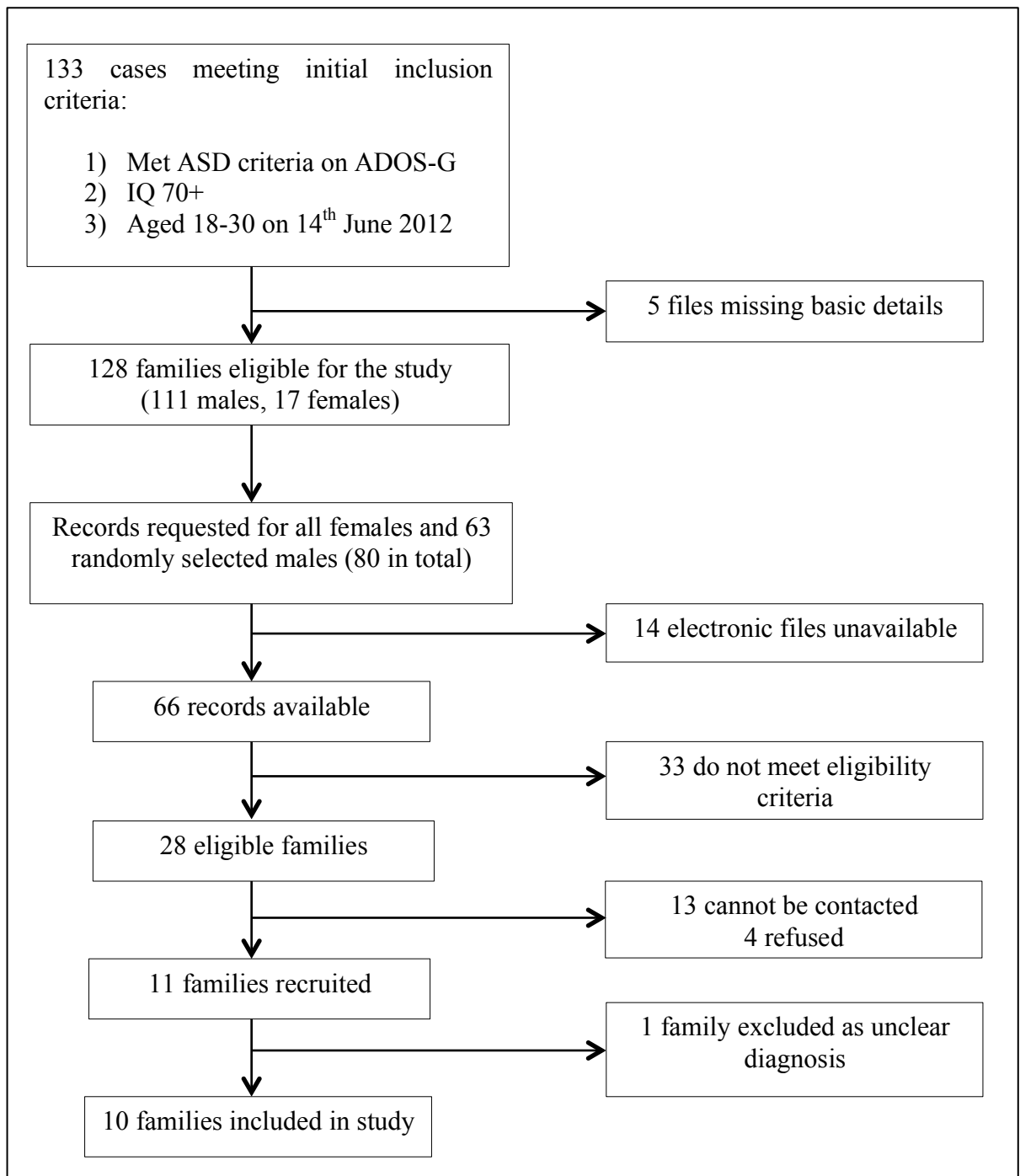


Figure 1. Recruitment and eligibility flow chart

Measures

Individual interviews. Participants were interviewed using semi-structured interview protocols developed for this study (Appendices 07 and 08). Face-to-face interviews were chosen for young adults and parents, as they may encourage more

thoughtful responses than telephone interviews and be more appropriate for research involving sensitive questions (Holstein & Gubrium, 2003). The interviews were semi-structured, providing the researcher an overall framework to ensure essential topics were covered, but also allowing flexibility for the researcher to have a naturalistic interaction and to deviate as needed to help engagement and explore emerging issues in more depth. The interview schedule was developed by the researcher and supervisors, with input from the service-user consultant. Topic areas covered in the interviews were developed with reference to the literature on adulthood outcomes in ASD discussed in Part 1 of this thesis, to ensure that key areas frequently cited in outcome literature were included. Therefore, questions were included on employment, education, friendships, relationships and independence.

Both young adult and parent interviews were designed to take under forty-five minutes. This is relatively short for a one-off interview covering a broad topic. However, we developed the interview mindful that social interaction with a stranger may be difficult for individuals with ASD and attempted to keep the interview of manageable length to avoid excluding young adults or parents who found a longer interaction difficult. Mean interview duration for young people was 40.3 minutes (SD 10.8), and for parents was 42.1 minutes (SD 11.2).

Participant Details Questionnaire (Appendix 09). A brief questionnaire developed for this study collected information about young adults' employment, education and current service use.

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Appendix 10). This is a fourteen-item measure of anxiety and depression symptoms; each item asks participants to select one of four statements that best applies to them. A sample anxiety item reads "I feel tense or 'wound up.'" Participants respond on a

four-point scale ranging from 0 = “Not at all,” to 3 = “Most of the time.” Higher scores indicate a higher level of symptoms. Seven items are summed to give a depressive score, and seven for anxiety. Therefore, each participant is given two scores (0-21), one for anxiety and one for depression. The original study of the scale suggests a score of eleven or more on either scale indicates caseness, and eight to ten a “doubtful case” (Zigmond & Snaith, 1983). However, more recent studies have suggested that eight is an optimal cut off (Bjelland, Dahl, Haug, & Neckelmann, 2002; Olsson, Mykletun, & Dahl, 2005).

The HADS was chosen as it is commonly reported in literature across a broad range of specialties and may be used as a brief measure of general distress (e.g. Norton, Cosco, Doyle, Done, & Sacker, 2013). A large-scale Norwegian study assessing the psychometric properties of the HADS identified two factors accounting for 57% of the variance, with anxiety items loaded on one factor and depression on the other. They report that anxiety and depression subscales were internally consistent (Cronbach’s alpha 0.76-0.80 for each) and correlated between 0.30 (overall sample) and 0.43 (participants with “mental problems”) (Mykletun, 2001). A comprehensive review concluded that with a cut-off score of eight, sensitivity and specificity of the HADS was between 70-90% (Bjelland et al., 2002).

Procedure

Interviews were conducted at participants’ homes, workplace or at the university base, dependent on participants’ preferences. In families where more than one person was interviewed, interviews were conducted separately unless participants requested otherwise. Two young people chose to be interviewed with a parent present. The interviewer checked participants’ understanding of the information sheet (Appendices 11 and 12), ability to retain the information, weigh up

the decision about whether to take part and communicate their decision, to ensure they had capacity to make the decision to take part (Mental Capacity Act, 2005). Participants were given the option to read a consent form (Appendix 13) themselves, or to have the form read to them before they agreed to take part. All participants were given a £10 Amazon.com gift voucher to thank them for their time before the interview began, and were reminded that they were able to decline answering any questions they did not wish to, and to end their participation at any time.

The Participant Details Questionnaire was then completed either in writing by the participant or as a brief interview, prior to beginning the main audio-recorded interview. Young adults completed the HADS at the end of the interview. They were given the option to complete it themselves, or to have questions read to them. Participation, including information sheets, consent forms and all measures took approximately one hour for each participant.

Analytic procedure

Interviews were transcribed verbatim using Express Scribe software (NCH Software, 2012). Data were analysed using a Framework Analysis approach (Ritchie, Spencer, & O'Connor, 2003; Ritchie & Spencer, 1994). Framework Analysis was chosen as it offers a well-defined process that promotes transparency in analytic procedures. The method was considered appropriate for this study as it allowed between-case and within-case analysis, and enabled the researcher to consider pre-determined research questions (Ritchie & Spencer, 1994). This approach has been used effectively in other research with people with ASD, and where comparisons between parent and child reports were required (e.g. Ruiz Calzada, Pistrang, & Mandy, 2011).

Initially, transcripts were read closely until I became familiar with the data. Anonymised transcriptions were entered into the Dedoose software (SCRC, 2011), and each idea that was relevant or potentially relevant to the research questions was tagged within the software as a “code” (Appendix 14). From a comprehensive list of these codes, I began to recognise recurrent themes and ideas emerging from the data. This process began whilst data collection was on-going, and the emerging themes were continually revised as more data were collected.

Codes were reviewed and grouped thematically into an initial conceptual framework. A consensus approach was taken to analysis; I took the lead, though emerging themes were regularly discussed with supervisors. Once the framework was agreed (Table 2), instances of each theme were indexed in every transcript. A thematic matrix was created (Appendix 17), allowing the data to be sorted by themes identified in the framework. All data indexed as relevant to a particular theme within the matrix was systematically reviewed to identify emerging representations of the theme, and synthesized to reach a descriptive account of the data. To ensure quality of the analysis, respondent validity checks were implemented at this stage (Stiles, 1993). Participants who had agreed to comment on the analysis were sent a summary of themes identified in their interview (Appendices 15 and 16). Reliability of this process was protected by frequent audits of the indexing process, and by regular discussions between myself and research supervisors to reach a consensus regarding the final analysis of the data.

Disclosure of researcher’s perspective

I am a white British female in my late twenties, completing this research project as part of a DClinPsy training course in London, UK. I have a background of working on research projects related to developmental disorders in adults, including

ASD and attention deficit hyperactivity disorder (ADHD), and an interest in increasing young people's access to mental health services. In my previous experiences of working with families affected by ASD, parents have commented on difficulties accessing post-18 support, and so at the beginning of the study I anticipated that the analysis might highlight unmet needs and a lack of appropriate support for adults with ASD. However, I attempted to set these expectations to one side during the interviews and data analysis. I was supported in doing this by regular discussions with supervisors and by taking a systematic approach to data analysis.

Results

Results from the HADS

All seven young adults completed the HADS questionnaire (Table 2). The mean HADS-D (depression) score was 3.57, below recommended cut-offs for caseness. The mean HADS-A score (anxiety) was 8.57, above the recommended cut-off for caseness of eight (Bjelland et al., 2002; Olsson et al., 2005). No young adults scored above this caseness cut-off for depression, but three showed a caseness level of anxiety, indicating a high prevalence of anxiety-related difficulties.

Table 2. HADS anxiety and depression scores

	HADS-D	HADS-A
YP01	0	6
YP02	5	13
YP03	4	11
YP04	3	7
YP05	6	9
YP06	7	6
YP07	0	1
<i>Mean (/21)</i>	<i>3.57</i>	<i>8.57</i>
<i>SD</i>	<i>2.8</i>	<i>2.6</i>

Framework analysis

Themes and subthemes. Transcripts of interviews with parents and young adults were analysed using Framework Analysis (Ritchie et al., 2003; Ritchie & Spencer, 1994). The thematic framework (Table 3) included four major themes: (1) experiences of being and parenting a young adult with ASD; (2) aspirations for adulthood; (3) barriers to aspired outcomes; and (4) engagement with talking about the future. Themes 1-3 focus on the content of interviews, whereas the fourth comments on the experience of completing the interviews, including the differences in perspectives of parents and young adults, and the extent to which young adults were able to speak about and plan for the future. Within these broad themes, nineteen subthemes are identified.

Quotes are labelled with “YP” for young person, “MO” for mother or “FA” for father, followed by a unique participant identifier. To preserve confidentiality between family members who have taken part independently, unique identifiers are not linked with other members of the same family or the family information given in Table 1.

1. Experiences of being and parenting a young adult with ASD. Seven subthemes emerged from the data under the broad theme of experiences of being and parenting a young adult with ASD, and so were included in the framework. Three related to interpersonal relationships (with friends, family and intimate partners) and the others to independence, interests and activities, employment and education, and support from others.

1.1 Supportive friendships vs. limited social relationships. All young adults spoke of having some social interaction. However, there was extensive variation in the frequency and quality in the relationships. Over half of the young adults

Table 3. Framework analysis and frequency of themes

		Frequency young adults (/7)	Frequency Parents (/13)
1. Experiences of being and parenting a young adult with ASD	1.1 Supportive friendships vs. limited social relationships	7	12
	1.2 Close family relationships in adulthood	7	13
	1.3 Intimate relationships	4	6
	1.4 Life skills and independence	7	11
	1.5 Stereotyped vs. creative and sporting interests	7	13
	1.6 Mixed experiences in education and employment	7	11
	1.7 Supported by others	7	13
2. Aspirations for the future	2.1 Returning or continuing education	7	6
	2.2 Spending time with others	7	13
	2.3 Pursuing careers	7	13
	2.4 Hoping to increase independence	7	13
	2.5 "I just want him to be happy"	n/a	9
3. Barriers to aspired outcomes	3.1 Difficulties interacting with others	6	13
	3.2 Economic barriers	6	12
	3.3 Limited independent living skills	4	13
	3.4 Physical health and emotional wellbeing	3	8
4. Engagement with talking about the future	4.1 Young adults more positive than parents	7 ^a	7 ^a
	4.2 "Talking the talk"	3	3
	4.3 Sparse vs. sophisticated thinking about the future	7	13

^a Theme present for all 7 families in which both young adults and parents were interviewed.

interviewed described valued, supportive and reciprocal friendships.

My friends are always there if I need them, or if I just want to have a chat. (YP06)

We all look out for each other. If anyone's struggling we try and help each other. Like if anyone's really hitting the dirt... we'll cook for them and stuff. (YP07)

Whilst the other three young adults interviewed identified themselves as having some friends, their accounts suggested more limited relationships; one young person described seeing friends once every few months, and another had seen friends outside of college twice over the past year. Between these extremes, one young person believed himself accepted to a degree that he was comfortable with, yet which might appear limited by conventional standards:

It's good to have friends. I mean some of the friends I've got at college... we are friends but we're not sort of like friends. I mean we sort of hang out, we're actually quite a quiet group. (YP03)

Parental views on friendship were also mixed. Notably, parents of young adults who did not take part in the study all identified their child as having limited social networks, suggesting young adults with more conventional social relationships were over-represented in this sample. Parents' views were consistently more negative than young adults'; parents from eight families had identified some limitation or concern about friendships, though no young adults did. However, parents often noted that their child might not necessarily want to be in more contact with others.

Some people are more upset by loneliness than others. I find that quite a difficult question with [my son really] in terms about how much being alone he finds lonely and how much of it he's not that bothered. (FA10)

Parents of the four young adults who gave rich descriptions of reciprocal friendships agreed that their child's friendships were both valuable and valued, even when they had some worries.

Her girlfriends seem to think a lot of her and they do support her. But sometimes... they cancel plans... and I do think to myself, "Is it because of the way she is?" (MO11)

1.2 Close family relationships in adulthood. Parents and family were typically identified as the most important people in young adults' lives and young adults almost exclusively reported close relationships with family members.

[Most important people are] my family and my friends, definitely. (YP05)

Parents often identified themselves as among the most important people in their children's lives, though parents also spoke of significant challenges in family relationships. Three parents reported significant difficulties in sibling relationships. For two families, both of whom had multiple children with ASD, this had escalated to serious violence between siblings. Parents from these families highlighted the difficulties for siblings of young adults with ASD.

I know it sounds terrible but she's had such a controlling impact on, I think people forget siblings.... When she came home from the mental home, they actually said, "Why didn't you leave her there?" (MO08)

We had a very bad time with both the boys. And they couldn't live together. I mean there was a stabbing, you know, and it was horrendous. It was [YP] who stabbed his brother but his brother provoked it. (MO14)

Some parents found their relationship with their child had improved as the child became older or more independent.

We've found a way of rubbing along together a bit better. (MO09)

In a similar pattern to that seen in social relationships, young adults typically reported fewer concerns about family relationships than parents. Notably, in families where parents reported most severe degree of family difficulties, such as violence between siblings, none of the young adults agreed to be interviewed. Therefore, the

young adults interviewed may present a biased view towards positive family relationships.

1.3 Intimate relationships. Six of the ten families reported that the young adults had current or previous intimate relationships, though it was at times difficult to get a sense of the quality of these relationships in the interviews. Parents from three of these families expressed concerns about the quality or sustainability of their child's intimate relationships. The children of these three families declined to be interviewed. Two parents spoke of their child experiencing difficult relationship breakdowns, one involving suspected financial exploitation, and another that led to a young adult with ASD being given a court order.

I think it got a bit nasty. Because I don't think [YP] knows when to back off sometimes when things are over... there's a molestation order... [YP] says she's messed up his head. And his friends are saying walk away but he can't seem to do that. (MO14)

However, parents also spoke of the positives of seeing their child in a relationship, and how this had shown a different side of their child. Young adults themselves also highlighted the subjective value of their relationships.

She seems to respond better, she's got more patience with the boyfriend, she doesn't let rip as much if you like, as she would if it was us. (MO11)

I suppose an ideal day, excluding my wedding day... I'd spend it with my partner and son. (YP02)

Young adults from half of the families included in this sample had some experience of intimate relationships. The current results show that whilst parents often have some significant concerns about their child's relationships, some young adults with ASD experience meaningful, valued relationships.

1.4 Life skills and independence. Seven young adults were living with parents or other family members, two were living independently and one in supported

accommodation. Parents of young adults living at home described them having limited independent living skills, and contributing little to maintaining the household.

I haven't seen any evidence of him being able to look after himself, but then that's because... his mum and dad are here. (FA10)

However, the young adults interviewed did not share these concerns. Young adults described themselves as helping out more often around the home than parents suggested, and developing an increasing sense of independence.

I do help out around the house occasionally now, although mum would disagree with that. (YP06)

I'm getting used to quite a lot of adult responsibilities. Like I can go out on my own and... I can get money out of the bank and pay in shops and things on my own so I guess [paying bills would be] just another thing to get used to. (YP04)

Despite parents' frequent concerns, several parents acknowledged their child's progress towards independence, and highlighted their child's ability to surpass their own and others' expectations in coping independently.

When he was much younger, I couldn't really see him getting to the point where he did live on his own, which he did do. So that was a nice surprise. I think he's achieved more than most people expected him to. (MO13)

Whilst some young adults had well developed skills that seemed comparable to their peers, there was evidence that most experienced some impairment. Young adults highlighted things that they were able to do, whereas parents highlighted the challenges and noticed the differences between their child and other people the same age.

1.5 Stereotyped vs. creative and sporting interests. Young adults and their families described varied interests. Some young adults were interested in activities stereotypically associated with ASD, i.e. repetitive hobbies with minimal social interaction, such as computer games:

I was thinking along the lines of becoming good and great in [computer] gaming. Because I think they actually have like... sports like the Olympics or something. (YP04)

However, many of the young adults were interested in a wider range of interests. Young adults from four of the ten families were interested in the arts, and three took part in extreme sports, including snowboarding and circus performing. Parents of these young adults spoke about the benefits they saw in their child's interests. For example, interests provided a shared topic of conversation and opportunities to meet new people, as well as career opportunities. This contrasted with the views of parents of young adults with fewer or more solitary hobbies, who raised concerns about their child's lack of activity, including concerns that they might be bored, missing opportunities, or wasting time.

1.6 Mixed experiences in education and employment. Young adults from six families had experience of employment or work experience, three of whom were interviewed. Positions held included administration roles, shelf-stacking and working in a call centre, animal park and café. One person was making money through online buying and selling, and another had had some initial success working towards music producing.

Whilst young adults did not identify any difficulties in employment, parents described holding more mixed views. Positive aspects included opportunities for young adults to become more independent and to pursue interests.

She's painting and clearing land and all sorts of things... So it's actually got her over her OCD... She really loves it there. (MO08)

In contrast, two families spoke about how impairments associated with ASD had presented challenges in maintaining employment, including difficulty respecting other people's space and vulnerability to workplace bullying.

He got some work experience at a vet's. Almost straight away the vet was saying this isn't working... he'd got inappropriate body language, partly because he wasn't respecting other people's space. (FA10)

A couple of [managers] thought he was being lazy or not cooperative or... But his heart was right, and probably he was doing as well as most people, to be honest... he [the manager] was a bully, basically. (FA18)

Educational experiences were similarly mixed. Some families and young adults described feeling well-supported in both specialist and non-specialist education settings. Helpful support came in the form of supportive and understanding staff and through intellectually challenging work and a hard-working ethos.

The tutors... were absolutely brilliant with her and um and so have the work experience because I phoned up and I said, "She's got Asperger's and OCD but just treat her like anybody else!" And they just took her in. (MO08)

However, difficulties in education were also highly prevalent. Young adults from three of the families were described as having poor school attendance. Educational difficulties included lack of appropriate support to help young people realise academic potential and schools being unable to meet a child's needs.

The whole education that... because I think if she'd had the right support, I mean she could have had a really good job now really. She'd probably have to do a job on her own, not with a team, but she's very bright and I think she could have got quite high qualifications. (MO08)

These results suggest that many young adults with ASD experience challenges finding appropriate education provision and employment. However, despite the difficulties associated with education and employment, there were significant successes; one young person was studying at a prestigious university, one had been signed to a digital music label to release a record and one was making money buying and selling items over the internet. This highlights that success is possible for young

adults with ASD if they are able to find education, employment or self-employment that fits with their interests, skills and needs.

1.7 Supported by others. All parents described providing some level of practical support, including parents of young adults living independently. Parents from seven families described their child needing support to manage personal administration tasks such as opening post and accessing benefits. Parents from three families described encouraging their child to find activities, work or education.

He's not very proactive. He relies totally up to now. Everything he does has been a result of... one of his parents has found, discovered and put his name forward and encouraged him. (FA10)

All young adults interviewed also commented on receiving support from their parents, though were less specific about the nature of this support. Four young adults spoke effusively about their gratitude at the degree of practical and emotional support offered within their family.

Only now am I starting to really kind of appreciate like how much she's [Mum] done for me. I'm blown away by how supportive she's been of me... I could never thank her enough. (YP07)

However, young adults overall identified fewer support needs than parents, and were less interested in finding support services. Views and experiences of support services were mixed. Parents highlighted a need for support, but they did not have consistent views on how a support service might be set up or what provision would be offered. Suggestions for helpful services included supported accommodation, ASD-specific education provision, jobs advice, support to link in with existing services, support for adolescence continuing into adulthood and support accessing benefits. One parent articulated the difficulty of knowing how support services could be provided:

My instinct is to say that lots would be helpful but I'm not sure exactly what. (MO11)

Parents also identified tensions between how much support to provide themselves and how to respond to plans they found unrealistic.

It's getting the balance between putting ourselves under a lot of pressure and molly-coddling her. (MO11)

I'm not quite sure whether I've done it for the better or the worse... a careful path between trying to help him be more realistic... without being a downer on his dreams. (FA10)

Whilst these findings highlight the support needs of some adults with ASD, they do not indicate a particular model of service provision that would be useful. For parents, a crucial aspect of effective service provision was having staff with an understanding of ASD.

The Job Centre are trying to help him but they don't fully understand. Clients with ASD seem like normal people so people think, 'what's the matter with him?'" (MO13)

None of the young adults suggested meeting other people with ASD would be helpful, although one commented that he would be curious to meet others. As no young adults with ASD requested an ASD-specific support service and parents highlighted the importance of staff understanding ASD, the findings suggest that training existing services in the support needs of people with ASD might be more appropriate than investment in specific services.

2. Aspirations for adulthood. Aspirations for adulthood contained four sub-themes for young adults and five for parents, which were included in the framework. Themes applicable to both parents and young adults were education, careers, independence and spending time with others. An additional theme emerging from parents' accounts was a focus on the child's happiness.

2.1 Returning or continuing education. All young adults and many parents expressed interest in future education or training. For some, education was an important part of their future, while others were less actively interested or engaged in pursuing it.

I couldn't imagine doing anything else with my life apart from going on to higher education. (YP07)

My biggest goal at ten or eleven was to excel academically but then it did change. (YP02)

Many young adults and parents hoped for education that allowed the young person to turn an interest into a career, such as pursuing art to work in graphic design, or an interest in computers.

I'd need to study the program I'm using on my Mac... a producers' kind of program... I've been trying to study that a bit more to become better myself. (PA09)

One parent suggested that it could be helpful to combine education tailored for people with ASD with education about a specific trade.

Education might be about... helping him to become more aware of how his autism is affecting him and how he might develop strategies to understand himself better and better enable [him] to deal with society. (FA10)

2.2 Spending time with others. Every participant spoke about spending time with others as a part of their own or their child's future. Some young adults spontaneously spoke about friendships and relationships when asked how they would like their future to be. However, for three of the seven, friendships were less salient in conversations about the future and spending time with others seemed less of a priority.

I think I might like to live with some other people I guess... I'm generally distant to sort of talk to someone because... I like sort of my alone time... but it would be good to... have some flat mates as well. (YP03)

Parents, particularly of the young adults who seemed less interested in social relationships, hoped that their child would spend more time with others in the future.

I think his life would be a lot better if he was able to form friendships, because otherwise you get terribly lonely... although he may not suffer [with loneliness] as much as some people. (FA10)

Perspectives on intimate relationships and having children in the future were also mixed. Parents almost exclusively said that they hoped their child would be able to have a relationship if they wanted one, though parents often seemed unsure whether this was something their child hoped for. Of the six young adults interviewed who were not currently in a relationship, five said they might like one in the future, and one did not comment. However, none presented finding a relationship as an imminent priority for them.

It's not a thing we've talked about much. He hasn't had any girlfriends or boyfriends or anything so in a partner's sense... I would guess if it could happen that would be great if it could happen, but then that's true for everybody. (FA10)

It would be nice [to have a relationship] but obviously it's not one of my main goals. (YP06)

2.3 Pursuing careers. All young adults and parents expressed hoped the young person would work in the future, and all families had some thoughts about what job they might have. Varied roles were suggested, including working with animals, becoming a champion computer-gamer, graphic design, music production and driving. Financial security was an important aspect of career decisions for young adults.

[I'm] looking forward to getting a well-paid job in the future. (YP03).

[I'd like to] go into academia and research... [But] I've got a bit of a caveat that I've got to be a bit more practical about it and that's very impractical... Research is very poorly paid. (YP07)

Parents prioritised their child finding a personally-rewarding job that the child could maintain over financial remuneration.

[I'd like him to] have a job to do and he can achieve something and he can get something done and he can feel you know, a bit of pride in himself. (FA10)

Parents and young adults had similar ideas about careers young adults might pursue. However, parents raised some concerns about their child's understanding of their aspired role, and about how actively they were pursuing their goals.

He probably thinks it's just driving the lorry [but] there's also a social interaction part to it. And I don't think he's really thought about... talking to customers and being polite to them. (MO19)

At one point he did have an ambition to be a chef... but I think it's more... of a habitual response now. (FA10)

During the current interviews, it was not possible to gather enough information to make an assessment of the objective likelihood that young adults would be able to follow their own plans. Certainly, young adults with ASD expressed interest in pursuing a varied range of careers. Whilst parents raised some concerns, there was a sense of hope amongst families that young adults would be able to work in adulthood.

I think he was born to be a scientist. (MO20)

2.4 Hoping to increase independence. All of the parents interviewed hoped that their child would become increasingly independent in the future. Of the six young people interviewed who were currently living with their family, five hoped to live independently. However, they did not necessarily want or expect this to happen soon.

I think he'd like to have his own place eventually as well. Although at the moment, he's quite comfortable here. I think

he'd like his own flat somewhere in the distance, perhaps.
(MO15)

In contrast, one young person did not aspire to living independently:

[I'd always like to live with Mum as] in my mind there's nothing wrong with that. You know, you always know that there's going to be someone to come home to at the end of the day that way. (YP06)

2.5 “I just want him to be happy.” One of the most commonly occurring themes for parents completing interviews was their aspiration for their child to do whatever it was that made them happy. Perhaps as a result, parents' reported aspirations often matched those of the young person, and when parents were asked what they hoped for in the future, they often answered in terms of what their child hoped to do or achieve.

I don't want him to achieve anything on my behalf. So whatever makes him happy is what I will want. But whether I know exactly what that is, I don't know. (PA07A)

3. Barriers to aspired outcomes. Barriers identified to achieving aspired outcomes by parents and young adults are included in the framework as four sub-themes. These relate to interpersonal difficulties, economic factors, independent living skills and barriers related to health and wellbeing.

3.1 Difficulties interacting with others. Interpersonal barriers were the most commonly identified barriers to young adults achieving their goals. These barriers manifested in a variety of ways, including communication skills, making judgements about social situations and vulnerability to others. One parent, for example, thought that this could impact on her daughter's ability to work with other people.

[She is] very articulate, very bright, but the communication is just not there at all... I just can't imagine her ever having her own job in which she's working with other people. (MO08).

Two of the seven young adults interviewed reflected on the social difficulties that are a core element of ASD, and showed an awareness of how this impacted on them now and in the future.

Taking things literally... I'm midway on sarcasm and quite good at [understanding] facial expressions. (YP02)

Eight parents and three young adults spoke about difficulties in judging social situations and responding appropriately, though their perspectives differed. Young adults spoke of being misunderstood or targeted by others, whereas parents spoke of their child misjudging situations and so behaving inappropriately, suggesting that they contributed to others' responses towards them. For example, YP06 and MO19 came from the same family and were interviewed together, and had different perspectives on the young person's experiences of being involved in altercations with others:

Some situations he gets into, I think he could have done something differently to have avoided the outcome. And because he didn't, he ended up being hurt or attacked. (MO19)

When I was attacked a couple of months back, when I walked in [to see Mum] after I reported it to the Police, I got told that it was my fault... what did I do wrong and blah blah blah. And it weren't really helpful, seeing as I hadn't actually done anything wrong. (YP06)

This example highlights important implications of social difficulties for young adults' safety. Eight parents also highlighted their concerns over their child's naivety or vulnerability to exploitation from others. Ramifications of this ranged from losing items after lending them to people to serious exploitation in relationships. For one family, this had serious consequences; the young person's boyfriend was suspected of spending her money, and was implicated in a burglary in which several thousand pounds in cash was stolen from the family home.

*My feeling was that... the boyfriend was cadging money. He wanted money because she'd been paying his rent. (MO08)
He can be slightly too trusting. He always sees the good in people. When he had his phone stolen, he thought he had lost it himself. (MO20)*

Parents identified concerns about social interaction more often than young adults, and described barriers as more severe than the young adults themselves. The risk of exploitation and experiences of being attacked by others highlight the importance and severity of interpersonal challenges faced by adults with ASD.

3.2 Economic barriers. Young adults from nine families were currently receiving significant financial support from their parents. Five parents spoke of the challenges associated with this, including wishing they could do more, and their experiencing of making sacrifices themselves to fund their child's needs.

He doesn't know exactly what he wants to do but he knows what he needs to do to give himself the best opportunity. Which is why even though I find it a real [financial] struggle, I'd rather make the sacrifice because I want him to achieve what he wants out of life. (MO20)

Several young adults spoke about financial barriers to their aspirations, and difficulties in finding employment in a difficult financial climate. This included challenges in funding education, concerns about choosing a personally meaningful career over a well-paid one, and the high cost of buying property.

I would like to go to university. I mean now it's very expensive and I'm not sure, but obviously if it were affordable then I'd love to. (YP03)

3.3 Limited independent living skills. Parents from every family identified limitations to the young person's independent living skills, in terms of managing chores, personal administration tasks and understanding their responsibilities. Given the prominent hope amongst all families that young adults would move towards

increasing independence, this could significantly interfere with their aspirations for the future.

I haven't seen any evidence of him being able to live independently. (FA10)

Notably, parents whose child was living away from home in independent accommodation also identified these impairments.

He's still not independent enough that he understands basic living skills. (MO20)

Young adults did not always agree with parents' concerns about their independent living skills, though some thought that some elements of independent living would or had presented challenges.

I do help out around the house occasionally now, although mum would disagree with that... [managing chores alone] doesn't really bother me that much as I've done most of them [before] already. (YP06)

3.4 Physical health and emotional wellbeing. Young adults from six of the ten families had experienced mental health problems. Two had specific diagnoses, OCD and depression. These and two others had been in contact with formal mental health services. Parents highlighted the severity of mental health difficulties encountered; one parent described her daughter being hospitalised for several months in adolescence, and another two parents expressed past concerns about their child harming themselves. Parents from a further family described their child as experiencing selective mutism and catatonia following severe bullying at school.

He came towards me and he was frozen. He didn't speak, at all. And as we got away from the college, his whole body softened and he started talking. It was like walking with a stone statue. (MO15)

Whilst each of these six families described their child's current mental health as improved, all but one reported some degree of residual difficulty. Young adults

from three of these six families were interviewed. Young parents described their mental health difficulties as less severe than parents did, but acknowledged some past and current challenges.

I do get upset a lot about the fact that I'm unemployed and about fear of financial distress that everyone feels, so when that pops into my head, that can get to me a lot. (YP02)

In addition to the more severe mental health difficulties identified by these families, all of the remaining four families spoke of current or past sub-diagnostic threshold symptoms. Two of these concerns were raised by parents; one parent raised concerns his son felt like “a loser,” (FA10) and another highlighted the challenge that puberty had presented her son.

Coming to terms with his body changing for puberty. That was a huge problem for [YP] ... He spent six months walking round with his eyes closed, avoiding mirrors... because he just couldn't look at himself. (MO12)

Other concerns were raised by young adults themselves; one young person spoke about the challenges of feeling misunderstood, whilst another spoke of anxiety about managing his anger in social situations following being attacked.

I go past the place it [being attacked] happened. So it is the fact of what will happen if I do see him again that was going through my head... when I'm in bed when I am alone, when I've got nothing to do that it all sort of comes back. And then I'll sit there sort of wondering and having a cry. (YP06)

Two young adults and four parents from five of the ten families spoke about anxiety in facing new situations as an on-going challenge for the young person. Whilst this was a common issue, it was not always perceived as prohibitive, and a number of families gave examples of times when anxiety had previously been overcome. For example, one parent described her daughter “nearly being sick in the toilet, she was like this [gesturing shaking]” (MO08) prior to beginning a college course. However, she found that her tutors were understanding and supportive and

completed the course, which lead to a rewarding long term work experience placement. This highlights anxiety as a prominent feature in the lives of young adults with ASD, which can make achieving goals more difficult but which may be overcome with appropriate provisions.

Physical health challenges were less prevalent than emotional difficulties. Two young adults had arthritis causing mobility impairment and pain; families commented on this being an added level of complexity in understanding their child's needs, and an additional concern for the future.

He's got arthritis which is flaring up again at the moment. Um, so, um, we're worried about not just how his autism affects him but also how the arthritis is going to affect him. (FA10)

4. Engagement with talking about the future. The themes related to being or parenting a young adult with ASD, aspirations for the future and possible barriers focused on the more concrete aspects of the interview transcripts. The final set of themes take a broader view of the interview process. They highlight the experiences of the interviewer conducting the research and address more process-oriented aspects of the findings.

4.1. Young adults are more positive than parents. Although similar themes emerged from parents' and young adults' interviews, across every aspect of the thematic framework, young adults consistently presented a more optimistic view of their experiences and their future than parents. Parents highlighted limitations in young adults' current social interaction, severe and frequent challenges negotiating family relationships and more limited independent living skills. Parents also expressed concerns or caution over their child's aspirations for the future, and anticipated more barriers for their child in meeting their goals. For example, one young person described his independent living skills to include travelling alone and

maintaining employment. The young person's mother, however, highlighted the young person's needs and the high level of support he required.

When we did leave him [for a holiday], it was a shambles. He lost his job. He couldn't get up. (MO17)

4.2 "Talking the talk." Stereotyped speech is a common feature of interactions with individuals with ASD. Some people with ASD are able to use stereotyped phrases in a way that suggests they have greater understanding of a topic of conversation than they may do. Whilst this can be helpful in allowing them to interact appropriately with other people, it can also mask some of the difficulties they face. Three parents spoke about their child using language that the parent did not believe matched the young person's understanding or experience. For example, both fathers who took part in the study commented on their child responding to questions about their aspirations for the future by stating aspirations they did not fully connect with or did not have.

[College] interviewed him and said what would he like to do. And he couldn't think of anything so he just told them what his mother's job was. (FA16)

At times, when interviewing young adults I found myself wondering whether their responses suggested stereotyped or rehearsed descriptions, rather than a genuine understanding or experience. For example, in this conversation about intimate relationships:

I've had a few girlfriends and it's all ended quite mutual actually, not... just between us both you know. Um and I have had a first love and that... that was... I hated how that ended, obviously. (YP05)

This description had a stereotyped quality that was noted both during the interview and in listening to the recording afterwards, but did not contain any specific information to suggest that the information was inaccurate. I experienced

similar concern during short sections of the interviews with three of the seven young people. Whilst I attempted to explore this further, the forty-five minute interviews limited the time available to do this.

These doubts related to a small part of interview material and were not objectively verified. Therefore, I do not believe that they had a substantial impact on the validity of the findings. However, they do highlight the difficulty of relying solely on self-report information in assessing outcomes. It is important to note that whilst parents were generally less positive than young adults, there was a great deal of similarity and overlap in young adults and parents' comments on current experiences, aspirations and barriers. Therefore, whilst these challenges of interviewing should be held in mind when interpreting data, they are not reason enough to discard data from individuals with ASD, nor a justification for excluding people from their own care planning.

4.3 *Sparse vs. sophisticated thinking about the future.* There was a great deal of variation in the extent to which young adults had considered the future. Two of the seven had evidently considered their future very carefully, including weighing up the pros and cons of a variety of options and taking into account a complex array of factors. One of the young adults had made some very clear plans about her family life, and commented:

So if things go to plan, my youngest baby will be about four. It sounds so specific! You see this is where the Asperger's becomes a little bit more obvious. I sounded relatively normal up to this point. (YP02)

Three young adults had given the future some thought, and were able to articulate their ideas reasonably well. In contrast, when interviewing two young adults, there was evidence of very limited thinking and planning for the future.

Notably, these were the same two young adults whose parents highlighted concerns

that they sometimes answered questions about the future with views that were not necessarily their own.

Hopefully I'll be quite successful with something maybe... I guess I don't really have that many expectations, or I don't know that many yet. (YP04)

I don't think future plans have got all that much to do with his life. (FA16)

The young adults with the most sophisticated thinking for the future were those with the highest IQ scores (assessed in childhood). It is plausible that those with IQ scores closer to the learning disability range might find planning for the future more difficult, or that they are encouraged less to do so. These examples highlight that within this sample, some young adults with ASD have given much more thought to the future than others, and young adults with ASD have varied capacities to consider options, plan for the future and articulate this process.

Respondent validity

Nine participants who agreed to comment on the analysis of their interviews were sent a two to three page summary of the themes identified in their interview (Appendices 15 and 16), and were invited to comment using a written or online form (Appendix 18). Two parents commented on the analysis, one to clarify her intention behind some of her quoted comments, and one to say that the themes very much captured her views, and to add some recent examples of her daughter's achievements, adding, "*Sometimes people with ASD can really surprise you.*" (MO20). These comments have been incorporated into the analysis.

Discussion

To our knowledge, this study represents the first attempt to consider outcomes for adults with ASD from their own point of view using qualitative methodology. Given the lack of available qualitative research investigating the views of adults with

ASD, this group are often a silent minority, yet the young adults' interviews in this study generated a rich dataset. They articulated varied and thoughtful ideas and demonstrated an interest and ability to plan for their future and reflect on their own experiences. Therefore, this study has achieved its aims of understanding participants' experiences of being or parenting a young adult with ASD, of their aspirations for adulthood and of potential barriers they faced in achieving their goals. The information gathered from young adults and parents allowed a tentative framework of outcomes for adults with ASD to be proposed as a tool for planning future research into understanding outcomes, and for assessing the needs and goals of individuals with ASD in clinical settings.

By utilising a qualitative interview method, this study took a phenomenological approach to understanding young adults' experience of their emergent adult life, and parental experiences of this under-researched post-childhood period. A notable finding was the variety in experiences. Whilst Part 1 of this thesis shows that the previously available evidence presents a picture of adults with ASD as lonely, under-employed and dependent on others, this is not the full picture. Whilst parents from every family interviewed identified some challenges in reaching adulthood for their child, some of the young adults were living independently, had successful relationships and supportive friendships. Young adults with lower levels of social interaction, less independence and more limited day-to-day activities were less concerned by this than their parents.

Many of the young adults interviewed were able to speak about their aspirations for the future, though it was not always easy to get a sense of how realistic young adults' plans were, or how engaged with pursuing these plans young adults were. Typically, parents and young adults spoke of similar aspirations,

primarily increasing independence, further training towards careers and supportive social contact. It was also a priority for young adults and parents to look towards good health and emotional wellbeing in the future.

Parents spoke of a range of challenges that parenting a young adult with ASD presented to them. This included arguments amongst the family and uncertainty as to whether they were providing the appropriate amount of support. Increasing independence was relevant for all families, including those families where the young person already lived away from home. In these instances, parents were often providing significant levels of support, including practical support with paying bills and claiming benefits, and financial support. Parents unsurprisingly highlighted the importance of their child being happy, and pursuing their own interests. These areas are broadly similar to some of those discussed in the literature, considered in Part 1 of this thesis, which included employment and education; independent living; mental health and quality of life. This gives some support to the concepts of outcomes commonly cited in the literature, but the present study also draws attention to some limitations of previous literature; systematic search of the literature failed to give a sense of the variety seen in this sample, including the more positive experiences of some young adults.

Families in the present study identified a number of barriers to meeting personal goals. The most common barrier related to interpersonal difficulties. Whilst some aspects of this were similar to interpersonal difficulties characterised in the literature (e.g. Gillespie-Lynch et al., 2012; Smith, Greenberg, Seltzer, & Hong, 2008), there was additionally a strong sense of participants' vulnerability to others. Whilst many children with ASD experience bullying and isolation from their peers (Chen & Schwartz, 2012), young adults in the present sample seemed at particular

risk of being exploited by others, or victimised. Examples included being exploited for money in relationships, or being overly trusting of others. This was a particular concern for parents of higher functioning individuals who were out on their own more often, as parents struggled to know how to manage this. Financial barriers were common, as were concerns about finding work in the current economic climate. This is similar to other similar age adults in the UK, where young people's unemployment rate is currently 19.2% (Office for National Statistics, 2013), but might be of particular concern to families concerned about how ASD might impact future employment opportunities.

Arthritis and mental health difficulties were present in this sample, consistent with previous research findings (e.g. Atladottir et al., 2009; Eaves & Ho, 2008; Hofvander et al., 2009). Two of the young adults interviewed experienced arthritis, which is more highly prevalent in autistic populations than general population samples (Atladottir et al., 2009). Parents and young adults also reported mental health diagnoses, including depression and OCD. More commonly, young adults and parents reported sub-threshold indicators of mental health or emotional well-being concerns, including high levels of anxiety, including a mean HADS anxiety score in the range of caseness.

The systematic literature search in Part 1 of this thesis tentatively suggested that higher functioning individuals with ASD might have less obvious impairments in adulthood that still had a significant impact on their lives. There is some indication of a similar trend in the present study. Young adults living independently and in relationships (whom therefore may well be considered to have a "positive" outcome in traditional outcome methodology) were reported to have on-going difficulties, particularly from the perspectives of their parents. These difficulties were indeed

more subtle in some ways, but it was evident that they still caused significant concern. For example, those living independently required significant levels of support from parents in managing personal administration.

The process-oriented themes emerging from the current dataset highlighted some of the methodological issues with the current approach to finding out about adults with ASD. Young adults consistently expressed fewer concerns about their current situation and their future than their parents. It was not possible using a one-off interview design to establish an objective view of the likely accuracy of these perspectives, though this was not the aim of this research. Whilst differences could represent under-reporting or lack of insight into difficulties for young adults with ASD, this might also be explained by parents having high levels of anxiety related to their child or underestimating their child's abilities.

Some of the young adults with ASD were somewhat reticent in their interviews. This encouraged the interviewer to ask more closed questions that are easier to answer, though doing so risks asking leading questions. During the analysis process, I endeavoured to maintain awareness of this risk. One of the commonly described features of ASD is a stereotyped style of speech (e.g. Geurts et al., 2004). At times during interviews I felt that some descriptions of relationships or plans for the future that seemed well thought out and articulate at face value did not represent authentic understanding, and were more similar to a rehearsed narrative. In the relatively brief interviews, limited by time constraints and with a wide range of areas to be covered, it was not always possible to cover these issues in the desired depth. This highlights one of the ways young adults with ASD were able to cover their difficulties, which their parents discussed more openly. Whilst this may help these

young adults function well in their own contexts, it can also prevent their needs being identified or supported.

Limitations

This study is one of the first attempts to understand the phenomenology of young adults with ASD's current lifestyle and their thoughts on their future. It has successfully provided some insight into the experiences of young adults and families, as well as demonstrating the variety of experiences not previously represented in the literature. However, the findings should be interpreted with reference to some limitations. The sample included in this study may not be representative of the wider population of adults with ASD. Although the age range was up to thirty years, all of the participants who took part were under twenty-five years old. Further, all participants had been seen in a specialist ASD service, rather than a local service. This might indicate that these young adults were assessed to be particularly complex in some way. However, as they were seen at the clinic a mean of almost ten years ago, they may have been referred simply due to the lack of ASD expertise in their area at the time. More parents than young adults were willing to take part in the interviews. All of the parents interviewed whose children did not take part reported significant concerns about their child's welfare and prospects. It is possible that the young adults taking part were those either more interested in sharing their experiences for research, or were more able to complete the interview process. Therefore, the present results might be overly optimistic if applied to the general population. However, as there is a plethora of research highlighting poor outcomes in ASD, the findings of variation in outcome in this study remains important.

The mechanisms by which some young adults with ASD might have more positive outcomes than others are not clear from this study. Perhaps unsurprisingly,

the young adults who were living independently and working tended to be those with higher IQ estimates (based on childhood assessments). In this predominantly qualitative design, this observation cannot be tested, but it does provide hypotheses for future quantitative investigation. This observation is also consistent with findings that the presence of a learning disability mediates the relationship between adaptive and cognitive functioning; Bolte and Poustka (2002), for example, found that in those without a learning disability, higher IQ was associated with greater adaptive functioning skills. Indeed, the IQ cut-off of 70 is frequently used to distinguish groups as this is conventionally used in the assessment of learning disability, but considering a non-categorical approach in future research might be helpful. Other potential mechanisms include relative severity of interpersonal difficulties or vulnerability, provision and access to appropriate support, parental variables and specific patterns of symptomatology within the autism spectrum.

Several parents described their young adult child as behind typically developing peers in terms of maturity. This highlights the importance of considering a young person's developmental stage, rather than chronological age, when working clinically. It is possible that a young adult with ASD might be tackling tasks typically associated with adolescence. In this way, it may be that adapting models of typical development is appropriate for working with people with ASD, rather than requiring a different model altogether. For example, Erikson's developmental stages identify the age of 13-18 years as a time of managing Identity vs. Role Confusion, a stage where children are becoming more independent and beginning to look at the future, thinking about careers, relationships, families and housing, for example (Erikson, 1950, 1968). Several of the young adults included in this study seemed to be negotiating this stage, despite being over 18, whereas others were perhaps

negotiating the next stage, Intimacy vs. Isolation (young adulthood) where the person's focus moves towards developing relationships outside of the family.

Proposed framework for understanding and assessing aspirations and outcomes

With reference to the themes emerging from the current study and the outcome literature considered in Part 1 of this thesis, a tentative framework for thinking about and working with adolescents and adults with ASD to achieve their own goals has been developed (Fig. 2). The intention of this framework is to highlight to people working with adolescents or adults with ASD the importance of considering the person's own valued aspirations and the barriers that they might face in different areas of their lives.

The first three major themes of the framework analysis (being, aspirations and barriers) each contained a number of subthemes. Within these subthemes, four areas were discussed particularly frequently: social interaction and relationships; independence; activity (including education and careers); and wellbeing. Therefore, the proposed framework is based upon these areas and highlights four life domains that are likely to be important: (1) satisfying contact with others; (2) health and wellbeing; (3) personally meaningful activity and (4) increasing independence. In Figure 2, each of the four domains is represented by one quadrant of the circle. The framework suggests that within each of these four domains, people working with individuals with ASD should consider the person's current experience in that domain (represented in the inner circle), their aspirations for the future in that domain (represented in the outer circle) and barriers that might present current or future challenges (represented in the middle circle). Notably, it is not necessarily the case that barriers in one area have an isolated impact on aspirations or current experience

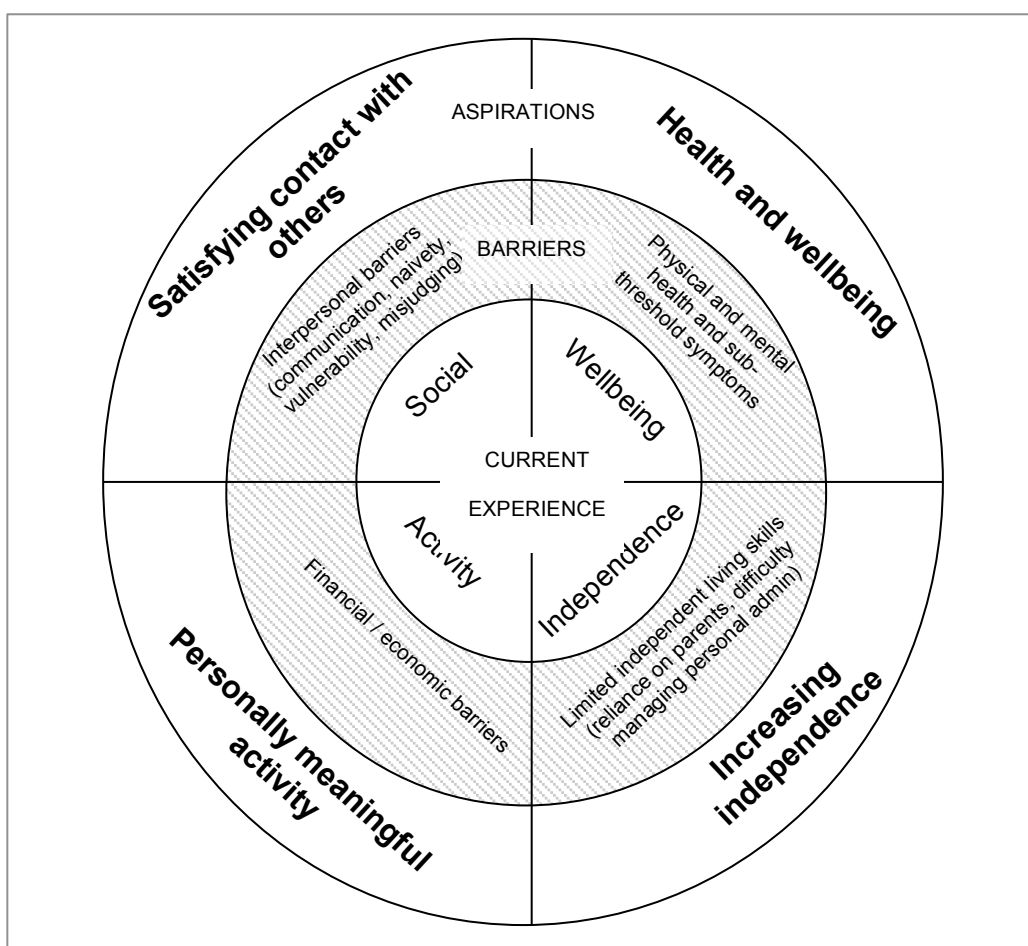


Figure 2. Proposed framework for understanding and assessing outcomes for people with ASD

in that area. According to the evidence gathered, some barriers present challenges across each of the domains. Poor communication skills, for example, are likely to impact on finding satisfying social contact, but might also impact on help-seeking for physical and emotional difficulties, and accessing meaningful activity.

Using this framework to assess individual experience, barriers and aspirations could help those working with a person with ASD to identify goals and support needs. Use of this framework could reduce the risk of important areas of a person's life being neglected and remind services to keep a client's own priorities at the heart of care provision. It is important to remember that the aspirations a person with ASD has in each area might be idiosyncratic. For example, as evidenced in the current

study, there is likely to be a great deal of variation in what “satisfying contact with others,” might be. For some of the young adults involved, this meant friendships that were comparable to those expected of a typically developing young adult. For others, interpersonal contact was less of a priority, though all stated they valued some.

Whilst this framework has been developed from data from a small group of young adults with ASD and their parents, it has potential applications beyond the current sample. The four domains that are highlighted overlap with domains investigated in quantitative literature (considered in Part 1 of this thesis). As there are few UK support services specifically for adults with ASD, any support they receive from statutory services is likely to be in mainstream services, where understanding and confidence in working with ASD might be limited. Therefore, a simple tool for highlighting the areas important to consider might be particularly beneficial. Part 1 of this thesis highlighted how outcome studies in ASD did not have a commonly agreed framework of areas contributing to adult outcome. Developing a framework such as the one proposed here might act as an initial step in developing a consistent and comprehensive approach to outcome assessment. Future investigations into how the framework proposed here fits outcome findings from other samples and from other methodologies and how it might be used in clinical practice will provide an assessment of its validity and utility.

Implications

The results from the current study have implications for research and for clinical practice. Future research might consider the differences between outcomes for those with intellectual ability significantly above the widely accepted learning disability range, and those with lower intellectual functioning. The findings suggest that those with a lower IQ (but not within the learning disability range) might be

vulnerable to poorer outcomes and having higher support needs, yet are unlikely to be eligible for many support services. Additionally, this study highlights the on-going concerns and challenges experienced by parents of young adults with ASD. Few parents receive any support with this. A challenge of working with parents of adults with ASD is that the client's consent is required for them to be involved in clinical care. However, there is scope for support groups, or for some way of preparing parents for the longer term challenges they might face in having an adolescent or adult child with ASD. Such support groups have previously been found helpful for parents of children with disabilities (Solomon, Pistrang, & Barker, 2001). Potentially, this need could be met within CAMHS services, prior to a child transitioning to adult service provision. Perhaps the most striking implication of the current findings relates to the variety of experiences of adults with ASD.

Whilst the results show on-going challenges, they also highlight the talents and successes of young adults with ASD. Whilst these are reported in the media, successes are widely ignored in research. Researchers and clinical teams can be encouraged to consider formulating positive outcomes, and investigating the mechanism of these successes, which may provide a framework for interventions that support people with ASD to pursue their own goals and make best use of their talents.

References

- Armstrong, J. (2011). Five famous autistic people throughout history. *Autism Support Network*. Retrieved from <http://www.autismsupportnetwork.com/news/5-famous-autistic-people-throughout-history-3543522>
- Arnett, J. J. (2000). Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469.

- Arnett, J. J. (2007). Emerging adulthood: what is it, and what is it good for? *Child Development Perspectives*, 1(2), 68–73.
- Aspirations For Life. (2012). Raising work aspirations for children and young people with learning disabilities. Retrieved from <http://aspirationsforlife.org/young-people-and-young-adults.html>
- Atladottir, H. O., Pedersen, M. G., Thorsen, P., Mortensen, P. B., Deleuran, B., Eaton, W. W., & Parner, E. T. (2009). Association of family history of autoimmune diseases and autism spectrum disorders. *Pediatrics*, 124(2), 687–694. doi:10.1542/peds.2008-2445
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531), 210–215.
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35(3), 351–360. doi:10.1007/s10803-005-3302-5
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale - an updated literature review. *Journal of Psychosomatic Research*, 52(2), 69–78.
- Bölte, S., & Poustka, F. (2002). The relation between general cognitive level and adaptive behavior domains in individuals with autism with and without co-morbid mental retardation. *Child Psychiatry and Human Development*, 33(2), 165–172.

- Chen, P., & Schwartz, I. S. (2012). Bullying and victimization experiences of students with autism spectrum disorders in elementary schools. *Focus on Autism and Other Developmental Disabilities*, 27(4), 200–212.
- Department of Health. (2010). Personalisation through person-centred planning. Department of Health. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115249.pdf
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(4), 739–747. doi:10.1007/s10803-007-0441-x
- Erikson, E. (1950). *Childhood and society*. New York: Norton.
- Erikson, E. (1968). *Identity: youth and crisis*. New York: Norton.
- Geurts, H. M., Verté, S., Oosterlaan, J., Roeyers, H., Hartman, C. A., Mulder, E. J., van Berckelaer-Onnes, I.A., & Sergeant, J. A. (2004). Can the *Children's Communication Checklist* differentiate between children with autism, children with ADHD, and normal controls? *Journal of Child Psychology and Psychiatry*, 45(8), 1437–1453. doi:10.1111/j.1469-7610.2004.00326.x
- Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders*, 42(2), 161–174. doi:10.1007/s10803-011-1222-0
- Henninger, N. A., & Taylor, J. L. (2012). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. Retrieved from <http://aut.sagepub.com/content/early/2012/08/16/1362361312441266.abstract>

- Hofvander, B., Delorme, R., Chaste, P., Nyden, A., Wentz, E., Stahlberg, O.,
Herbrecht, E., Stopin, A., Anckarsater, H., Gilberg, C., Rastam, M., &
Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with
normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9(1), 35.
doi:10.1186/1471-244X-9-35
- Holstein, J., & Gubrium, J. (2003). *Inside interviewing: new lenses, new concerns*.
California: Sage.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children
with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212–229.
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian
Journal of Psychiatry*, 57(5), 275–283.
- IRIS. (2012). IRIS guidelines update. Early Intervention in Psychosis IRIS Network.
- Lord, C., Risi, S., Lambrecht, L., Cook, E., Leventhal, B., DiLavore, P., Pickles, A.,
& Rutter, M. (2000). The Autism Diagnostic Observation Schedule -
Generic: A standard measure of social and communication deficits associated
with the spectrum of autism. *Journal of Autism and Developmental
Disorders*, 30(3), 205–223
- Mental Capacity Act (2005). Retrieved from <http://www.legislation.gov.uk/ukpga/2005/9/contents>
- Mykletun, A. (2001). Hospital Anxiety and Depression (HAD) scale: factor
structure, item analyses and internal consistency in a large population. *The
British Journal of Psychiatry*, 179(6), 540–544. doi:10.1192/bjp.179.6.540
- NCH Software. (2012). *Express Scribe*.

- NICE. (2012). Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. NICE clinical guideline 142. National Institute for Clinical Excellence. Retrieved from guidance.nice.org.uk/cg142
- Norton, S., Cosco, T., Doyle, F., Done, J., & Sacker, A. (2013). The Hospital Anxiety and Depression Scale: a meta confirmatory factor analysis. *Journal of Psychosomatic Research*, 74(1), 74–81. doi:10.1016/j.jpsychores.2012.10.010
- Office for National Statistics. (2013). *Labour Market Statistics*. Retrieved from <http://www.ons.gov.uk/ons/rel/lms/labour-market-statistics/march-2013/index-of-data-tables.html#tab-Unemployment-tables>
- Olsson, I., Mykletun, A., & Dahl, A. (2005). The Hospital Anxiety and Depression Rating Scale: a cross-sectional study of psychometrics and case finding abilities in general practice. *BMC psychiatry*, 5(1), 46.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In *Analysing Qualitative Data*. London: Routledge.
- Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out qualitative analysis. In *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.
- Ruiz Calzada, L., Pistrang, N., & Mandy, W. P. L. (2011). High-functioning autism and Asperger's disorder: utility and meaning for families. *Journal of Autism and Developmental Disorders*, 42(2), 230–243. doi:10.1007/s10803-011-1238-5
- Saldana, D., Alvarez, R. M., Lobaton, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009). Objective and subjective quality of life in adults with autism

- spectrum disorders in southern Spain. *Autism*, 13(3), 303–316.
doi:10.1177/1362361309103792
- SCRC. (2011). *Dedoose*. Retrieved from www.dedoose.com
- Smith, L., Greenberg, J., Seltzer, M. M., & Hong, J. (2008). Symptoms and behavior problems of adolescents and adults with autism: effects of mother–child relationship quality, warmth, and praise. *American Journal on Retardation*, 113(5), 387–402. doi:10.1352/2008.113:387–402
- Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29(1), 113–132.
- Stiles, W. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593–618.
- Taylor, J., & Seltzer, M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40(12), 1431–1446. doi:10.1007/s10803-010-1005-z
- Taylor, J., & Seltzer, M. (2011). Changes in the mother–child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(10), 1397–1410.
doi:10.1007/s10803-010-1166-9
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370.

Part 3: Critical appraisal

Introduction

This appraisal considers some of the conceptual and practical issues raised during the process of this research. In the first section, issues related to designing and conducting research with people with ASD whilst taking a phenomenological approach are considered. This includes the challenges and considerations in developing qualitative methods appropriate for use with this client group, involving a service user in the research process and the implications and limitations of making contact with young adults via mothers. The second section considers the implications of the current findings for service provision within the current NHS context, and the similarities and differences between individuals with ASD and their typically developing peers.

Phenomenological research and ASD

Developing qualitative measures for people with ASD

The social interaction difficulties inherent in ASD may have discouraged researchers from developing qualitative interview methods or undertaking phenomenological research with people with ASD. A challenge in developing the interview schedule for young adults in this study was the need to balance the importance of asking non-leading questions to avoid influencing participants' answers (Legard, Keegan, & Ward, 2003) with an awareness that abstract, open-ended questions might be particularly difficult for interviewees with ASD. In developing interview schedules for this study, I attempted to manage this by incorporating a mixture of questioning styles and taking a flexible approach to adapting my interview style and pacing to meet the needs of the participant. Questions in both interview schedules included open and closed, abstract and concrete questions. Building rapport with interviewees is essential in qualitative

interviewing; one way of doing so is to begin interviews with questions interviewees feel most able to answer (Jacob & Furgerson, 2012). Therefore, both parents and young adults were asked about their interests in the first section of the interview. Once draft interview schedules had been developed, they were refined in conjunction with feedback from the service user consultant, discussed in the following section.

When conducting the interviews, I found the flexibility in the interview schedules both helpful and necessary, as conducting the interviews presented a number of challenges. At times, interactions with participants seemed stilted and uncomfortable, and at other times I found it difficult to interrupt participants and to stick to the interview schedule. I believe that my previous experiences of working with adolescents and young adults with ASD, and previous experiences of completing semi-structured interviews with other client groups, were important in enabling me to facilitate these interviews successfully. For example, from my experience of conducting assessments using the Autism Diagnostic Observation Schedule (ADOS-G) (Lord et al., 2000) I approached the interviews in this study with some insight into the challenges of initiating and maintaining conversations with individuals with ASD, and some confidence in tolerating sometimes uncomfortable social interactions, with individuals who might not offer some of the expected conventions of social interaction.

Involving service users in the research process

A service user consultant volunteered to provide input on research design and measure development. The consultant's input was undoubtedly helpful in considering the challenges that someone with ASD might face in answering open-ended questions, and in suggesting follow up questions to support individuals finding open or abstract questions difficult. It was not always possible to fully incorporate

the consultant's views on the interview schedule, as at times this conflicted with some features I considered essential in meeting the research aims. For example, the interview schedules were designed to begin with open questions about what young adults or parents hoped for in the future, to avoid biasing answers, before becoming more specific throughout the interview. The consultant suggested removing these early questions, as she considered them to be ambiguous in their phrasing, and not tailored enough to the unique issues faced by people with ASD. From my perspective as the researcher, I was mindful of the importance of giving participants the opportunity to generate their own ideas, which is best achieved by using open questions. Therefore, I concluded that a balance needed to be struck between making the interview schedules accessible to people with ASD and not asking questions that would be too challenging to answer, and being true to a phenomenological approach. I managed this by holding in mind the concerns of the service user consultant during the interview, especially in the most open questions, and being careful to adapt my interview style to each participant, and by asking more concrete and specific follow up questions as needed. This issue highlights how consulting to a research study could be a frustrating experience for service-user consultants if it is not possible for their ideas to be fully incorporated. I hope that by explaining the rationale behind decisions about which ideas to incorporate and which not to, I was able to manage this in a way that resulted in a positive experience for the service user, and that was beneficial for the study.

Having completed twenty-one research interviews, I believe that the service user consultant's ideas were helpful, and were incorporated appropriately into the study protocol and measures. Several participants with ASD managed the most open questions well, and provided rich and detailed responses, but more specific questions

were useful in supporting participants who found these more difficult. I believe that to have removed open questions would have denied young adults a genuine opportunity to speak about their own experience and aspirations, and would have inappropriately assumed one person's view represented the whole target population.

Whilst I spent some time with the research consultant explaining the nature of the study and my rationale for the approaches used, I believe that I could have taken more time over this, and explained my rationale behind each section of the interview and the order of the questions with greater clarity earlier. In future, I would prioritise sharing my reasoning and rationale explicitly with a service user prior to asking them to review measures. This would, however, need to be approached with care to ensure this involved giving the consultant a full understanding of the approach, rather than promoting the planned research design.

Mothers as a primary point of contact

The participants in this study were young adults and their parents. Given the nature of the research design, the contact details available for inviting families to take part were those given to the clinic during young adults' childhood assessment. For all of the families included in this study, this was the contact information for one or both parents. As a result, for all but one family, the mother was the first family member to speak with the research team and so was the one to put me in contact with their son or daughter. Parents and young adults had been told in their invitation letters that their parent or child would also be contacted, and that one was able to take part even if the other party did not want to. In initial phone contact with parents, I emphasised the voluntary nature of the research, and that they should not give me their child's contact details without the young person's explicit permission. Several parents said that their child would prefer for me to make arrangements via the

parents to complete the interviews, which I agreed to do. This approach allowed me to be flexible to families' requests and preferences, and allowed young adults who may have felt anxious or apprehensive about speaking to a stranger over the telephone to be included in the study.

Whilst I believe making contact via mothers in this way was a practical necessity for the project, I had some reservations about the approach. Mothers often volunteered to arrange interviews for their child, and whilst I emphasised the voluntary nature of the interviews in these conversations, this meant that I was not party to conversations about the study. Particularly for young adults who were more reticent in the interviews themselves, I wondered how much they had been encouraged or persuaded to take part. During the interviews, I managed this by reminding participants about their right to withdraw, or to not answer any questions they did not want to. No participants chose to withdraw from the study. Another risk of contact being made via parents is that this might infantilise or patronise young adults. For this reason, it is preferable to speak directly to young adults where possible, but to balance this with allowing families to support young adults to take part if they wish to.

It is difficult to know whether the correct balance was achieved in this study. Certainly fewer young adults would have taken part if mothers had not been involved in arranging initial contact, passing information between young adults and myself and arranging appointments. Young adults were less willing to take part than parents; young adults from thirty percent of the families in the study declined to be interviewed. As I had not had any contact with the young adults directly, I was not able to hear the reasons they did not wish to participate. There may be differences in the families who did and did not take part, and who were and were not contactable.

Whilst the small sample in the current study may not be representative of the population of young adults with ASD, the rich data provided by the families who did take part has allowed hypotheses to be generated for future larger scale and/or quantitative investigation.

Conflicting views between parents and young adults

Parents and young adults did not always agree in their interviews, particularly in relation to the severity of young adults' impairments and the barriers they might face now and in the future. During the interviews and the analysis, I noticed a temptation at times to assume that parents' less optimistic views presented a more valid description than young adults' own interviews. Given that this study did not include any objective measures of young adults' abilities or of barriers they faced, it would be inappropriate to give either parents' or young adults' accounts more priority. Therefore, in the analysis I have presented both young adults' and parents' views, and avoided making judgments about discrepancies in parents and young adults' views. The systematic nature of framework analysis, which includes systematically reviewing and indexing each transcript according to the framework, was a helpful tool in maintaining an appropriate level of objectivity in the analytic process.

One-off interviews cannot tell the full story

This study utilised one-off interviews to speak with young adults and parents about their current aspirations and their plans for the future. Arnett (Arnett, 2000, 2007) highlights the transitional nature of the emerging adulthood period, implying that between the beginning and end of this period, there will be a great deal of change. Young adults in the current study had a mean age of 20.6. In some ways, interviews at this age are both too early and too late to fully answer the research

questions posed. Young people's lives, their aspirations and their perspectives on barriers are likely to change between their early twenties and the end of the emerging adulthood period, yet conversely many key decisions have already been made at this time. For example, young people in their early twenties have made decisions about leaving or continuing education, and some have become much more independent of their parents. For these reasons, prospective follow up studies of young people with ASD using qualitative methodology and a phenomenological approach would be helpful in developing a better understanding of the experiences of young adults with ASD, and their perspective on the future.

The interviews used in this study attempted to cover a wide range of areas in relatively brief one-off interviews. The interviews were deliberately broad to allow participants to speak about whatever aspects of their current experience or their future were meaningful to them. However, as a result, many topics were covered in a short space of time. Therefore, it was not always possible to consider each topic raised in as much detail as would have been preferable. This made it difficult in some interviews to find out the extent to which young adults and parents had considered different options for their future, and to explore issues beyond the most salient themes (e.g. housing, work). Longer or repeated interviews might have allowed these issues to be considered in more detail. However, this would also have required a much bigger time commitment from participants, and was beyond the realistic scope of this study. Further, given that some young adults in particular were noticeably reticent during interviews, it may not have been fair to them, or beneficial to the research, to have longer or repeated interviews.

Implications and applications of findings

Using these findings in UK statutory service provision

Given the high levels of difficulties reported in this study, particularly from the perspectives of parents, it would be understandable to argue that statutory services should offer support for adults with ASD into adulthood. This might involve services to meet their mental health needs, to offer specialist support in accessing activities such as employment or education, or support in developing interpersonal or independent living skills. However, in the current political and economic context, it seems unlikely that funding such a service specifically for adults with ASD would be feasible. However, this does not mean that these findings cannot contribute to offering more accessible and effective support services. Given the lack of ASD-specific services, and that the adults included in the current sample would not be eligible for learning disability services, any services that they do access are likely to be mainstream statutory provision.

Several families spoke about contact with mainstream further education colleges, and with the benefits and Job Centre systems. The findings of this and other similar studies can be used to support mainstream services to meet the specific needs of adults with ASD. The framework proposed in Part 2 of this thesis could be used as a tool to guide staff in their interactions with adults with ASD. For instance, the framework highlights the importance of considering four domains of current and future experience, some of which are likely to be neglected currently. As adults with ASD might enjoy or value idiosyncratic hobbies or careers, and social relationships that do not fit conventional norms, it is easy for their own valued outcomes in these areas to be overlooked, for example. Providing access to this framework for teachers, social workers and employment advisors, for example, might helpfully highlight to them of the importance of considering the individual's priorities in each of these areas. This approach of providing a framework for working with adults with ASD

that can be used not only by clinicians, but by professionals or support staff from all backgrounds, fits with current UK priorities for care provision, including personalisation of services and person-centred care (Department of Health, 2010; National Institute for Clinical Excellence, 2011).

Are young adults with ASD different to typically developing young adults?

Arnett's (2000, 2007) concept of emerging adulthood highlights the many tasks faced by young people between their late teens and late twenties, including exploring their own identity, becoming more independent and negotiating relationships. Similar themes are also reflected in Erikson's Identity vs. Role confusion and Intimacy vs. Isolation developmental stages (Erikson, 1950, 1968) covering the adolescence and young adult period. Both approaches overlap with the findings of this study. Therefore, it seems that the priorities for young adults with ASD are reminiscent of typically developing young adults.

However, there are factors unique to individuals with ASD that may make achieving in these domains more difficult for adults with ASD, and that can lead to people around them overlooking their needs and wishes in some of these areas. Firstly, the priorities of people with ASD might be expressed in an idiosyncratic way. For example, the meaning of "satisfying relationships with others" might look quite different to conventional friendships. Additionally, young adults with ASD face particular barriers in each of these domains that are less frequently encountered by their typically developing peers. For example, the naivety and vulnerability to exploitation highlighted in the current study can make developing satisfying relationships with others more difficult, and can make the people supporting an individual with ASD (e.g. parents, support staff) wary of allowing someone with ASD the independence to create these relationships. Further, the barriers faced by

people with ASD might be well-concealed, particularly for those with higher IQ. Difficulties may be covered by well-developed compensatory strategies, by a stereotyped manner of speaking that implies a greater understanding than an individual has and by adults with ASD having limited insight into their own difficulties.

Conclusion

The issues considered here demonstrate the flexible approach to adapting empirical methods needed to use phenomenological approaches with individuals with ASD. Although adaptations were necessary, such as a flexible approach to the level of structure provided for participants during interviews, this study successfully demonstrated that such research can be conducted in a meaningful way with people with ASD. Unsurprisingly, parents and young adults at times had different views. In this study, in future studies and within service provision, there is a risk of parents' views being prioritised over the views of individuals with ASD themselves. Whilst parents and other people close to individuals with ASD may often be able to offer valuable insight into support needs, it is important to remember that adults with ASD have the right to give their own views and to make decisions about their lives and their care. Systematic analysis methods in research can help ensure that young people's views are given appropriate weight when they disagree with parents or other people involved. In clinical and statutory support settings, individuals with ASD should be supported to work towards their own valued goals and outcomes, as this study demonstrates their willingness and ability to do so.

References

- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469.

- Arnett, J. J. (2007). Emerging adulthood: What is it, and what is it good for? *Child Development Perspectives*, 1(2), 68–73.
- Department of Health. (2010). Personalisation through person-centred planning. Department of Health. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115249.pdf
- Erikson, E. (1950). *Childhood and society*. New York: Norton.
- Erikson, E. (1968). *Identity: youth and crisis*. New York: Norton.
- Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: tips for students new to the field of qualitative research. *Qualitative Report*, 17, 6.
- Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. In *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.
- Lord, C., Risi, S., Lambrecht, L., Cook, E., Leventhal, B., DiLavore, P., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule - Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223.
- National Institute for Clinical Excellence. (2011). *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (Clinical Guideline No. 128)*. Retrieved from <http://eprints.hud.ac.uk/14569>

Appendices

Appendix 01: Quality and relevance assessment scale

Appendix 02: Studies excluded from literature review

Appendix 03: Ethical approval

Appendix 04: Ethics committee receipt of amended documents

Appendix 05: Invitation letter (young person)

Appendix 06: Invitation letter (parent)

Appendix 07: Interview schedule (young person)

Appendix 08: Interview schedule (parent)

Appendix 09: Participant details questionnaire

Appendix 10: Hospital Anxiety and Depression Scale (HADS)

Appendix 11: Information sheet (young person)

Appendix 12: Information sheet (parent)

Appendix 13: Consent form

Appendix 14: Example of coded transcript

Appendix 15: Respondent validation example (young person)

Appendix 16: Respondent validation example (parent)

Appendix 17: Extract from thematic matrix

Appendix 18: Respondent validation form

Appendix 01: Quality and relevance assessment scale

**ADAPTED FROM NEWCASTLE-OTTAWA QUALITY ASSESSMENT
SCALE
(COHORT STUDIES)**

Italics represent changes from original assessment scale

Note: A study can be awarded a maximum of one star for each numbered item within each category.

Selection (Max 3*)

- 1) Representativeness of the exposed cohort (*initial sample*)
 - a. Truly representative of the *average adult with ASD* ✱
 - b. Somewhat representative of the *average adult with ASD* ✱
 - c. Selected group of users (*e.g. using specialist service or with a particular need*)
 - d. No description of the derivation of the cohort
- 2) *CRITERION 2 (SELECTION OF THE NON-EXPOSED COHORT)
REMOVED AS NOT APPLICABLE TO CURRENT REVIEW*
- 3) Ascertainment of *ASD diagnosis*
 - a. *Diagnosis confirmed with validated measures (e.g. ADOS-G and ADI-R)* ✱
 - b. *Evidence of comprehensive assessment by a health professional* ✱
 - c. *Self or parent report of diagnosis*
 - d. No description
- 4) *CRITERION 4 (DEMONSTRATION THAT OUTCOME OF INTEREST WAS NOT PRESENT AT START OF STUDY) REMOVED AS NOT APPLICABLE TO CURRENT REVIEW*
- 5) Sample size
 - a. *Fifty or more adults with ASD included* ✱
 - b. *Less than fifty adults with ASD included*

Control (Max 1*)

- 1) Appropriate control for significant confounding factor
 - a. Study controls for *learning disability* or *IQ<70 in analysis* such that it is possible to draw conclusions about ASD independent of learning disability ✱
 - b. *Participants with learning disability, IQ<70 or below 'normal range' excluded* ✱

- c. *Learning disability or IQ not controlled for*
- d. *Learning disability or IQ not reported*

Outcome (Max 5*)

1) A. Assessment of outcome

- a. *Appropriate outcome measures (e.g. objective measurement, validated tools) **
- b. *No description or inappropriate measures*

1) B. Personally valued outcomes (e.g. fulfilment of own aspirations)

- a. *Measures of participants' own valued outcomes attempted**
- b. *Personally valued outcomes not considered*

2) Was follow-up long enough for outcomes to occur (longitudinal studies) OR Were participants beyond early adulthood (cross-sectional or other studies)

- a. *Yes (mean age at final time point >25)**
- b. *No*

3) Adequacy of follow up of cohorts (Longitudinal studies only)

- a. *Complete follow up – all subjects accounted for **
- b. *Subjects lost to follow up unlikely to introduce bias – small number lost <25% or description provided of those lost*
- c. *Follow up rate <75% and no description of those lost*
- d. *No statement*

4) Range and relevance of outcomes considered

- a. *Outcomes in a range of areas of life assessed **
- b. *Comprehensive analysis of outcome(s) in one area of importance*
- c. *Limited outcomes considered or outcomes reported in little depth*

Appendix 02: Studies excluded from literature review

Studies excluded from OVID and MEDLINE search

Exclusion reason	Frequency
Genetic or physiological study	10
Book review	1
Child sample	6
Duplicate	2
Experimental manipulation or intervention	4
Sample with learning disability	20
Non-ASD sample	11
Non-human sample	2
Non-outcome variables	1
Parent/carer outcomes only	4
Review or conceptual paper	6
Total excluded	67

Appendix 03: Ethical approval

NRES Committee North West - Preston

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: (
Facsimile: (

16 January 2012

Dr William Mandy
Clinical Psychologist
Research Dept of Clinical, Educational and Health Psychology
UCL, 1-19 Torrington Place
London
WC1E 7HB

Dear Dr Mandy

Study title: Perspectives on reaching adulthood, adult aspirations
and outcomes in people with autism spectrum disorders
(ASD)
REC reference: 12/NW/0073

The Proportionate Review Sub-committee of the NRES Committee North West - Preston reviewed the above application by correspondence.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

1. The Committee would like to see the patient information sheet revised to:
 - a) Include the sentence 'You are welcome to bring something that reflects your interests to talk about if you wish'.
 - b) Include the sentence 'Direct quotes (what you actually said) may be used in writing this project. You will not be identified from these.'
 - c) Include a further point "I understand that the recording can be rewound, stopped at any time and words deleted or changed"
2. The Committee would like to see the Consent Form revised to
 - a) Include the standard clause "I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information"
 - b) include provision to consent to the use of anonymised direct quotes in the write up.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of insurance or indemnity		07 December 2011
Interview Schedules/Topic Guides	Young person - 1.7	29 December 2011
Interview Schedules/Topic Guides	Parent - 1.4	29 December 2011
Investigator CV	William Mandy	
Investigator CV	Dr Chris Barker	
Investigator CV	Zoe Huntley	
Letter of invitation to participant	Parent - 1.1	13 December 2011
Letter of invitation to participant	Young adult - 1.1	13 December 2011
Participant Consent Form	1.7	29 December 2011
Participant Information Sheet: Parent	1.6	29 December 2011

Participant Information Sheet: Young person	1.6	29 December 2011
Protocol	2.6	29 December 2011
Questionnaire: HADS		
Questionnaire: Participant Details Questionnaire	1.6	29 December 2011
REC application	3.4	05 January 2012
Referees or other scientific critique report		21 October 2011

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0073

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Patricia Wilkinson
Chair

Email: p.wilkinson@nres.nhs.uk

Enclosures: List of names and professions of members who took part in the review

"After ethical review – guidance for researchers"

Copy to: Dave Wilson, University College London
Mr Subhir Bedi, Great Ormond Street Hospital NHS Trust & ICH

Appendix 04: Ethics committee receipt of amended documents

NRES Committee North West - Preston

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 275 4444
Facsimile: 0161 275 4445

31 January 2012

Dr William Mandy
Clinical Psychologist
Research Dept of Clinical, Educational and Health Psychology
UCL, 1-19 Torrington Place
London
WC1E 7HB

Dear Dr Mandy

Full title of study: Perspectives on reaching adulthood, adult aspirations
and outcomes in people with autism spectrum disorders
(ASD)
REC reference number: 12/NW/0073

Thank you for your email of 29 January 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 19 January 2012. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	1.8	26 January 2012
Participant Information Sheet: Parent	1.7	26 January 2012
Participant Information Sheet: YP	1.7	26 January 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/NW/0073	Please quote this number on all correspondence
-------------------	---

Yours sincerely

Miss Diane Catterall
Assistant Co-ordinator

E-mail: d.catterall@nhs.uk

Copy to: Dave Wilson, University College London
Mr Subhir Bedi, Great Ormond Street Hospital NHS Trust & ICH

Appendix 05: Invitation letter (young person)

[Clinic Headed paper]

Young adult invitation letter v1.1 13/12/2011

[DATE]

**Re: Invitation to take part in a research study
Aspirations, transitions and outcomes in people with autism spectrum disorders (ASD)**

Dear [NAME]

You might remember attending the Social Communication Disorders Clinic at Great Ormond Street Hospital in [YEAR]. The clinic is currently running a study in partnership with University College London about the things young adults with autism spectrum disorders want in life, and the things that are important to them. We are contacting you now to invite you to be a part of this research.

The research involves having one informal meeting with a researcher, and you will be offered a £10 Amazon.com gift voucher to thank you for your time. An information sheet about this study is included with this letter, which gives you more details. We will contact you by telephone in two weeks' time to ask if you would like to take part.

Please bear in mind that if it is a long time since you attended the clinic, our contact details for you may be out of date. If you think this might be the case, you can let the researcher know by email (z.huntley@ucl.ac.uk) or in writing at the address below (no stamp needed). You are also welcome to get in touch if you have any questions, or if you would prefer not to hear from us.

**FREEPOST University College London, WC1E 6BT
Department of Clinical, Educational and Health Psychology
(Attention Zoe Huntley, DClinPsy trainee)**

We look forward to hearing from you,

Dr W Mandy
Clinical Psychologist

Appendix 06: Invitation letter (parent)

[GOSH Headed paper]

Parent invitation letter v1.1 13/12/2011

[DATE]

**Re: Invitation to take part in a research study
Aspirations, transitions and outcomes in people with autism spectrum disorders (ASD)**

Dear [NAME]

You might remember attending the Social Communication Disorders Clinic at Great Ormond Street Hospital in [YEAR] with your [SON/DAUGHTER]. The clinic is currently running a study in partnership with University College London about the things young adults with autism spectrum disorders want in life, and what their parents' hopes and priorities are for them. We are contacting you now to invite you to be a part of this research.

The research involves having one informal interview with a researcher, and you will be offered a £10 Amazon.com gift voucher to thank you for taking part. An information sheet about this study is included with this letter, which gives you more details. We will contact you by telephone in two weeks' time to ask if you would like to take part.

Please bear in mind that if it is a long time since you attended the clinic, our contact details for you may be out of date. If you think this might be the case, you can let the researcher know by email (z.huntley@ucl.ac.uk) or by post at the address below (no stamp needed). You are also welcome to get in touch if you have any questions, or if you would prefer not to hear from us.

**FREEPOST University College London, WC1E 6BT
Department of Clinical, Educational and Health Psychology
(Attention Zoe Huntley, DCLinPsy trainee)**

We look forward to hearing from you,

Dr W Mandy
Clinical Psychologist

Appendix 07: Interview schedule (young person)

"I'm working on a research project to find out a bit about what young people want out of life, and I'm hoping you can help me out with it. I'll be asking you some questions about the things you like and don't like to do, and about how you see your life changing in the future. The questions have no right or wrong answers. I really want to know what you think or feel, so it would really help if you could try your best to tell me what you think, and not what you think I might like you to say. It'll take about 45 minutes."

Main question

Potential follow up questions (if needed, dependent on response and timing)

Hobbies and interests

[IF YOUNG PERSON HAS BROUGHT SOMETHING TO THE INTERVIEW]

Would you like to tell me a little about what you have brought with you?

1. What are your main interests at the moment?

Is that something you've always liked/liked doing?

Do you think you'll always like it?

Do you think you'll still be going to X / doing X in ten years' time?

Do you have any other hobbies or interests?

What were you really into when you were sixteen / at school / in primary school?

General questions

2. Are you at school/college/university at the moment?

How long do you plan on staying in education?

What would you like to do afterwards?

Have you started anything or planned anything that hasn't worked out?

3. Do you have a job or do any voluntary work at the moment?

Is that something you like?

Would you like a job?

What would your dream job be?

Have you always wanted to do that?

How might you be able to get that job?

What might get in the way of that?

What would be good / bad about it?

Would you want future/current employers to know about your ASD diagnosis?

4. At the moment, what are the best and worst bits of your week?

What's the best/worst thing about that?

So if you could describe an ideal day for you, what would that be like?

5. What things are you satisfied with or happy about in your life at the moment?

What are you not happy with in your life at the moment?

6. How often do you think about what things will be like when you are older?

What do you think about?

Do you make plans for the future?

7. If you think about yourself and your life in ten years' time, what would you like your life to be like?

How do you think it'll actually be?

Are there things you need to do for that to happen?

Is there anything that might get in the way of that?

8. You've told me that in the future you would like to have/achieve/do X. Is that what you've always wanted?

Did you ever have hopes or plans you've given up or changed your mind about?

What changed your mind?

What were you really into when you were 16?

9. If I had a magic wand, and could give you the life of someone else – maybe someone you know or someone famous – whose life would you want?

What would be so good about that?

Are there any downsides?

Daily living

10. Would you like to live where you do now for a long time?

Where would you like to live and who with?

What would be nice about that?
Who would do the housework and pay the bills?
Is there anything that might make moving there difficult?

11. If you had a day to do whatever you wanted, what would you do?

What do you do with your free days at the moment?
How might you organise that?
Is that something you think you might be able to do in the future?
What could get in the way?

12. You've told me you'd like to have / do X, X and X in the future. Have you thought about how you might pay for those things?

How much might it cost?
Who pays for the things you do at the moment?

Interpersonal Relationships

12. Who are the most important people in your life at the moment?

Do you think they will always be important to you?
How often do you think you will see them/your family in 5/10/20 years' time?

13. Are you in (or would you like to be in) a relationship?

What might be good about having a partner?
What might be difficult?
What would you like them to be like?
Is physical intimacy important to you?
Is a potential partner knowing about or understanding ASD important for you?

14. Apart from your family, do you enjoy spending time with other people?

Have you stayed in touch with people from school?
Would you have liked to stay in touch with more people?
Is having friends important to you?
Is being accepted by people around you important to you?
In the future, would you like to have other / more / the same friends?
Why might that be good / bad?
How might you make new friends in the future?

What sort of things would you like to do with friends in the future?

Do you or would you like to see colleagues outside of work?

15. Sometimes people go to social groups for people with ASD, or have individual support workers to go with them on outings, maybe shopping or to do an activity like bowling. Is that something you would like?

Would that be the same as going out with friends?

How might that be different?

Which would you prefer?

Transition

“Now I’d like to move on and ask you a few questions about your experiences over the past few years.”

16. What’s different now from when you were at school?

What’s good and bad about that?

What was it like leaving school?

Was it as you expected?

On your last day of school, did you have plans for what happened next?

Have you done the things you’d planned to?

17. What’s been the best thing about becoming an adult?

What’s been the worst or most difficult thing?

Did you want / get any help with that?

Is there anything about becoming an adult you would like/ have liked help with?

Who would you have liked that help or support to come from?

Concluding

18. Are there things we haven’t talked about that you think are important in your future?

19. Do you think your parents want the same things for you?

20. What are you most looking forward to in the future?

Appendix 08: Interview schedule (parent)

“I’m working on a research project to find out a bit about what young adults with ASD want out of life, and about what their parents want for them. I’ll be asking you some questions about the things that [YOUR CHILD] wants for the future, and about what you want for them. I’m also trying to find out more about what it’s like for young people with ASD and their families as they make the transition from adolescence to adulthood. It’ll take about 45 minutes.”

Main question

Potential follow up questions (if needed, dependent on response and timing)

Introduction and hobbies

“I’ll ask some broad questions first to get a sense of your thoughts, then return to some of the details later.”

1. What are [your child]’s interests at the moment?

Has that always been the case?

How do you think [your child]’s interests or priorities might change in the future?

2. When you think about the future, what are the main things that you hope for for [your child]?

3. What do you think would make [your child] happy in adulthood?

4. In 10 years’ time, how do you hope things will be different from now for [your child]?

What impact would those changes have on you and the rest of the family?

What do you think will need to happen for [your child] to achieve that?

Do you think he/she wants the same things for him/herself?

Do you think there is anything that could get in the way of those things happening?

Daily living / education and employment

5. What do you think is important for [your child] in terms of on-going or future education?

6. What do you think about how [your child] spends his/her time at the moment?

What might you or they like to be different?

What difference would those things make?

Is there anything that could get in the way of making those changes?

7. Do you think or hope that [your child] will always live with you/where they are now?

What do you think about that?

How would [your child] feel about and manage independence?

Is their independence important to you?

8. What are your hopes for [your child] in terms of employment or career?

Is that something that you think could happen?

What might be difficult for [your child] in employment or in that career?

What might suit them about that job/career?

9. What do you think about [your child]’s own plans for his/her future?

Are they realistic?

Is [your child]’s plans for the future something (s)he discusses with you?

10. Has [your child] tried anything that hasn't worked out?

Why do you think it didn't work?

Interpersonal Relationships

11. Who are the most important people in [your child]’s life at the moment?

Do you ever see that changing in the future?

How does [your child] get on with you and the rest of the family?

How do see your role in [your child]’s life in the future?

12. What are your thoughts on [your child]’s relationships outside of the family?

What is the quality of these relationships?

Are they satisfying for [your child]?

How important do you think these relationships are for [your child] in adulthood?

13. Is it important to you for [your child] to have a relationship and/or a family of his/her own?

What do you think [your child] thinks about that?

Do you think that (s)he will have a relationship/family in the future?

What do you think [your child] would find difficult about being in a relationship?

Independence

14. How independent do you hope for [your child] to be in the future?

What do you think [your child] thinks about that?

What would need to happen or change for [your child] to be more independent?

How independent is (s)he at the moment?

What could get in the way of [your child] having greater independence?

15. Do you hope or expect that [your child] will need or receive any support from the state in adulthood? (e.g. supported accommodation, social group)

What do you think [your child] thinks about that?

Do you know whether these services are available?

Transition

16. How have things changed for [your child] since leaving school/college/university?

17. How has [your child] changed since then?

18. Do you think of [your child] as an adult now?

19. What has been the most difficult thing about the transition to adulthood for [your child]?

20. What do you think has been the best thing about becoming an adult for [your child]?

21. What has the period of [your child] becoming an adult been like for you and the family?

Has it been as you expected?

What has been difficult?

What positive changes have there been?

22. Do you think [your child]’s hopes and expectations for the future have changed over the past five years?

How?

Can you think of any ways you might have influenced his/her hopes and expectations for the future?

Can you think of anything else (people or experiences) that might have influenced his/her hopes and expectations?

Concluding

23. Are there things we haven't talked about that you think are important in [your child]'s future?

24. Do you think (s)he wants similar things for him/herself?

25. What do you think [your child] might most look forward to in adulthood?

What do you most look forward to for them?

Appendix 09: Participant details questionnaire

PARTICIPANT DETAILS QUESTIONNAIRE v1.6 29/12/2011.

Please complete this brief questionnaire, which will take less than five minutes.

Ask the researcher if you have any questions.

Today's date: __ / __ / __

Gender: *Male / Female*

Date of birth: __ / __ / __

1. Where do you live at the moment?

☐ *with parents or family*

☐ *alone (owned)*

☐ *supported accommodation*

☐ *other* _____

☐ *with friends or housemates*

☐ *alone (rented)*

2a. What is your current employment status?

☐ *employed (full-time)*

☐ *employed (part-time)*

☐ *unemployed*

☐ *student*

2b. If you are employed, what is your job? _____

2c. If you are a student, what are you studying? _____

3a. What sort of secondary school did you attend?

☐ *Mainstream school*

☐ *Specialist school*

☐ *Specialist unit within a mainstream school*

3b. Did you have a statement of special needs at school?

☐ *Yes*

☐ *No*

4. What is your highest qualification?

- | | |
|--|--|
| <input type="checkbox"/> <i>no qualification</i> | <input type="checkbox"/> <i>GCSE (or equivalent)</i> |
| <input type="checkbox"/> <i>AS Level or equivalent</i> | <input type="checkbox"/> <i>A Level or equivalent</i> |
| <input type="checkbox"/> <i>undergraduate degree</i> | <input type="checkbox"/> <i>postgraduate qualification</i> |

5a. Are you in contact with any mental health or support services at the moment?
(This may include services provided by your employer, college or university).

- ☐ *Yes* ☐ *No (go to Q6)*

5b. If so, which services?

5c. How often do you see them?

5d. What support / service do they give you?

6. Do you have any diagnoses, other than ASD? *Please give details.*

- ☐ *Yes (please give details)* ☐ *No* ☐ *Prefer not to say*

7. Would you like to receive information about the outcome of this study?

- ☐ *Yes (please give contact details below)* ☐ *No*

Appendix 10: Hospital Anxiety and Depression Questionnaire (HADS)

(Zigmond & Snaith, 1983)

Hospital Anxiety and Depression Questionnaire

[Removed due to copyright]

Appendix 11: Information sheet (young person)

Perspectives on reaching adulthood, adult aspirations and outcomes in people with autism spectrum disorders (ASD)

PARTICIPANT INFORMATION SHEET (YP) [v1.7 26/01/12]

You are being invited to take part in a research study based at University College London (UCL). Before you decide whether to take part, we would like you to understand why the research is being done and what it involves. Please talk to others about the study if you wish, and ask us any questions you have. Part 1 of this sheet tells you about the study and what will happen if you decide to take part. Part 2 gives you more detailed information about the conduct of the study. This information sheet is yours to keep.

PART 1

What is the purpose of the study?

The study aims to gain a better understanding of the things that young people with an autism spectrum disorder find important to them, and the things they hope for in the future.

Why have I been invited?

We are inviting young adults who have previously attended the Social Communication Disorders Clinic at Great Ormond Street Hospital to take part in this study. We are also inviting parents of people who have attended the clinic to take part, and so your parent may also be invited. You can take part whether or not your parent decides to.

Do I have to take part?

Whether or not you take part is completely up to you. We can discuss the study with you, and talk through this information sheet. If you decide to take part, we will ask you to sign a consent form. You are free to change your mind at any time, and do not need to give us a reason. This does not affect any care you may be receiving now, or may receive in the future.

What will I have to do?

If you decide to take part, a researcher will arrange to meet with you at a time and place that you choose. The researcher will ask you some questions about yourself, such as your interests and hobbies, and the things you hope to have or do in the future. The researcher will also ask about what your experiences of becoming an adult have been. There are no right or wrong answers; the meeting is to find out about your experiences and views. You are welcome to bring something that reflects your interests to talk about if you wish.

The interview will take around 45 minutes and will be audio-recorded. You can ask for the recording to be rewound or stopped at any time, and for words to be changed or deleted. We will also ask you to complete two brief questionnaires. If both you and your parent are taking part, we will interview you separately unless you would prefer us to meet you together.

What are the possible benefits of taking part?

We will offer you a £10 gift voucher for Amazon.com to thank you for your time. We hope that many participants will enjoy speaking about their hopes and plans for the future. If you take part, you will be given the opportunity to comment on our findings and to receive the final report of our findings.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages of taking part in this study. You can withdraw from the interview at any time, or decide not to answer any of the questions if you do not wish to. If you like, we can provide you with details of organisations that may be able to offer you support.

Will my taking part in the study be confidential?

Yes. We will follow ethical and legal guidelines about confidentiality, and all the information about you will be handled in confidence. The details are included in Part 2.

PART 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, and do not need to give a reason. If you wish, all information you have already given will be withdrawn from the study and destroyed.

What if there is a problem or something goes wrong?

Any complaint about the way you have been dealt with during the research or any possible harm you might suffer will be addressed. Every care will be taken in the course of this study. However, in the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr W Mandy, who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this. Regardless of this, if you wish to complain, or have any concerns about the way you have been approached or treated by members of staff or about any adverse events you may have experienced due to your participation in the research, the normal National Health Service complaints mechanisms are available to you. Please ask the researcher if you would like more information on this. Details can also be obtained from the Department of Health website: <http://www.dh.gov.uk>.

Will my taking part in the study be kept confidential?

Anything you tell the researcher will be treated as confidential. Your information will be stored in an anonymous form, labelled by a number and not by your name and accessible only to the research team. The only exception to confidentiality is if you tell us something that puts you or someone else in danger. In this exceptional circumstance, we may need to break confidentiality. We would make every effort to discuss this with you first. All data will be collected and stored in accordance with the Data Protection Act 1998.

What will happen to the information I give you?

The interviews will be transcribed (written up) and then the recording will be erased. This information, any written notes, and your consent form, will be stored securely at UCL, and only the researchers involved in the study will have access to it.

What will happen to the results of the research study?

The information will be analysed along with the things that other families tell us and presented in a final report. Direct quotes (what you actually said) may be used in writing this project. You will not be identified from these. You may be invited to comment on a draft of the final report if you wish to, though there is no obligation to do so. No individuals or families will be identifiable from the report. You will be sent a copy, if you would like.

Who is organising and funding the research?

This research is organised by University College London, in collaboration with the Social Communication Disorders Clinic at Great Ormond Street Hospital.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by an NHS Research Ethics Committee.

Further information and contact details. Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information. You can contact the research team by calling xxx or by emailing xxx.

Appendix 12: Information sheet (parent)

Perspectives on reaching adulthood, adult aspirations and outcomes in people with autism spectrum disorders (ASD)

PARTICIPANT INFORMATION SHEET (Parent) [v1.7 26/01/12]

You are being invited to take part in a research study based at University College London (UCL). Before you decide whether to take part, we would like you to understand why the research is being done and what it involves. Please talk to others about the study if you wish, and ask us any questions you have. Part 1 of this sheet tells you about the study and what will happen if you decide to take part. Part 2 gives you more detailed information about the conduct of the study. This information sheet is yours to keep.

PART 1

What is the purpose of the study?

The study aims to gain a better understanding of the things that young people with an autism spectrum disorder find important to them, and the things they hope for in the future.

Why have I been invited?

We are inviting parents of young people who have previously attended the Social Communication Disorders Clinic at Great Ormond Street Hospital to take part in this study. We are also inviting young people who have attended the clinic themselves to take part, and so your child may also be invited. You can take part whether or not your child decides to.

Do I have to take part?

Whether or not you take part is completely up to you. We will discuss the study with you, and talk through this information sheet. If you decide to take part, we will ask you to sign a consent form. You are free to change your mind at any time, and do not need to give us a reason. This does not affect any care you may be receiving now, or may receive in the future.

What will I have to do?

If you decide to take part, a researcher will arrange to meet with you at a time and place that you choose. The interviewer will ask you some questions about your son or daughter, such as their interests and hobbies, and the things you hope for them in the future. The researcher will also ask about what your experiences of them becoming an adult have been.

The interview will take around 45 minutes and will be audio-recorded. You can ask for the recording to be rewound or stopped at any time, and for words to be changed or deleted. If both you and your child are taking part, we will interview you separately unless you request otherwise.

What are the possible benefits of taking part?

We will offer you a £10 gift voucher for Amazon.com to thank you for your time. We hope that many participants will enjoy speaking about their child's aspirations for the future. If you take part, you will be given the opportunity to receive the final report of our findings, which may be of interest to you.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages of taking part in this study. You can withdraw from the interview at any time, or to decide not to answer any of the questions if you do not wish to. If you like, we can provide you with details of organisations that may be able to offer you support.

Will my taking part in the study be confidential?

Yes. We will follow ethical and legal guidelines about confidentiality, and all the information about you will be handled in confidence. The details are included in Part 2.

PART 2**What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any time, and do not need to give a reason. If you wish, all information you have already given will be withdrawn from the study and destroyed.

What if there is a problem or something goes wrong?

Any complaint about the way you have been deal with during the clinical trial or any possible harm you might suffer will be addressed. Every care will be taken in the course of this study. However, in the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr W Mandy, who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this. Regardless of this, if you wish to complain, or have any concerns about the way you have been approached or treated by members of staff or about any adverse events you may have experienced due to your participation in the research, the normal National Health Service complaints mechanisms are available to you. Please ask the researcher if you would like more information on this. Details can also be obtained from the Department of Health website: <http://www.dh.gov.uk>.

Will my taking part in the study be kept confidential?

Anything you tell the researcher will be treated as strictly confidential. Your information will be stored in an anonymous form, labelled by a number and not by your name and accessible only to the research team. The only exception to confidentiality is if you tell us something that puts you or someone else in danger. In this exceptional circumstance, we may need to break confidentiality. We would make every effort to discuss this with you first. All data will be collected and stored in accordance with the Data Protection Act 1998.

What will happen to the information I give you?

The interviews will be transcribed (written up) and then the tape will be wiped. This information, any written notes, and your consent form, will be stored securely at UCL, and only the researchers involved in the study will have access to it.

What will happen to the results of the research study?

The information will be analysed along with the things that other families tell us and produced in a final report. Direct quotes (what you actually said) may be used in writing this project. You will not be identified from these. You may be invited to comment on a draft of the final report if you wish to, though there is no obligation to do so. No individuals or families will be identifiable from the report. You will be sent a copy of this, if you would like.

Who is organising and funding the research?

This research study is organised by University College London, in collaboration with the Social Communication Disorders Clinic at Great Ormond Street Hospital.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by an NHS Research Ethics Committee.

Further information and contact details. Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information. You can contact the research team by calling xxx or by emailing xxx.

Appendix 13: Consent form

Perspectives on reaching adulthood, adult aspirations and outcomes in people with autism spectrum disorders (ASD)

PARTICIPANT CONSENT FORM [v1.8 26/01/2012]

This study has been approved by the NRES Ethics Committee North West - Preston
(Project ID: 12/NW/0073).

Thank you for your interest in taking part in this research. Before you agree to take part, the researcher must explain the project to you. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time. Please read the following statements. If you understand and agree with each one, tick the box and then sign at the bottom.

I have read the notes written above and the Information Sheet, and understand what the study involves	
I understand that if I decide at any time that I no longer wish to take part in this project, I can tell the researchers and withdraw immediately	
I understand that the recording can be rewound, stopped at any time and words deleted or changed	
I agree to the processing of my personal information for the purposes of this research study	
I agree for the researcher to access my clinical case notes for the purpose of this study	
I understand that my information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998	
I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.	
I understand that the information I have submitted will be published as part of a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications	
I understand that my participation will be audio recorded and I consent to use of this material as part of the project	
I understand that direct quotes (what I actually said) may be used in the report, but that these will be anonymised and I will not be identifiable from them.	
I would be interested in giving my comments on the analysis of interviews before results are published. I agree for the researcher to contact me about this	
I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study	
I would like a copy of the write-up of this study	

Name:

Researcher name:

Signature:

Signature:

Date: __/__/____

Appendix 14: Example of coded transcript

	Transcript	Initial codes	Framework
R:	When you think about the future, what are the main things that you hope for, for him?		
FA18:	Um well any father or mother, parent, wants their children to be happy. So you don't want you know, want that they be a this or that. But within that to feel fulfilled. I guess [mother] and I would like him to meet a nice woman who, not takes care of him, but who is able to um balance the side of things which he struggles with. Because he's a lovely young man. And I'm sure he could uh... that would work fine. Um but anyone such as X you know he's got to provide, be a part-provider shall we say, and that's still an area that's difficult for him.	<p>Prioritises happiness and fulfilment</p> <p>Wants YP to be in caring relationship</p> <p>Providing is a challenge</p>	<p>2.07 Parent focus on YP's aspirations</p> <p>2.02 Intimate relationships</p> <p>3.03 Independent living skills</p>
R:	And so if you think about, say ten years' time, how do you hope things will be different from how they are now day-to-day in his life?		
FA18:	Yeah I think I would hope that um he might well be in a position where he could get his own place and be able to manage. Um uh and that his work will have got him to some position where he's able to work. If not full time then at least to have some level of success and income. Because he studies at the moment.	<p>Hopes YP can live independently</p> <p>Hopes will work and earn money</p>	<p>2.06 Increasing independence</p> <p>2.03 Careers</p>
R:	Absolutely. And what impact would those changes, say if he had his own place, what would it be like for you and the rest of the family?		
FA18:	Um well uh quite... quite a lot. Because um, although... we're kind of just used to it now. And many parents have their children stay and have different problems, so it can be... but that's no good for your children. Though our daughter stayed pretty much... though she was travelling as a ski instructor so she wasn't home a lot between 18 and 25 really (laughs) so it's, you can't really compare. But um... sorry what was the question again?	Comparisons between children	
R:	So how do you think it would be different		

for you and the rest of the family if he had his own place?

FA18:	Uh I think it would be different. We'd be pleased for him. But we would imagine it would be fairly local so we could sort of always be at hand, be available for um... But it would free [mother] and I a bit more. To do things we might wish to do. To go away and things like that, which are not so easy to do. And we've got a dog! (Laughs) But apart from that, it would give us a bit more space.	Hope to live independently Parents provide support Difficult for parents to go away	2.06 Increasing independence 1.07 Support from others
R:	Um a lot of it's kind of subliminal. We do things without probably realising, you know. But um... it's not really difficult. X eats very restricted things. You know, chicken kiev, certain foods. Just three or four pieces, it's quite repetitive. So eating as a family is you know quite difficult. Hard. I wouldn't say non-existent, for a roast he would come out on a Sunday. But um no it's more um like if he goes out with friends, I've always got an ear to where he's... it's not chasing him up, but do I need to offer to come and get him (R: Okay). And often I will go out at two or three in the morning you know, just you know, I'd rather get him home than him walk back and you know get hit or something. I'm quite protective, you could say. But understandably I think. In that um so you do feel a bit more on call. He spends quite a bit of time on his own anyway. So it's not, not... I don't want to paint it the wrong way (laughs). Um but I think he's just uh you know... there's a certain amount of worry involved (R: Hm). Shopping for clothes is non-existent. He does a few things online, but we still get things and take them back and it's... I wouldn't say it's necessarily hugely different to a normal person staying, a son or whatever. But um you've probably got different challenges with everyone. So I'm not saying it's difficult, it's not.	Restricted diet Difficult to eat as family Parent supports by collecting from night out Vulnerability Spends time alone Parent's worries Parents support with clothes shopping	1.07 Support from others 3.06 Interpersonal barriers 1.01 Interpersonal relationships 3.03 Independent living skills 1.07 Support from others

Appendix 15: Respondent validation example (young person)

PRIVATE & CONFIDENTIAL

Aspirations and outcomes for people with autism spectrum disorders (ASD)

Summary of themes (Participant ID: YP01)

Your hopes for adulthood:

- 1) Living independently
 - You told me that you would like to get your own place to live in the future, perhaps with some friends.
- 2) A job linked to your interests
 - You hope to have a job that you are interested in in the future. For example, you would like to be a chef.
 - You know that chefs must work long hours and this would be difficult, but hope you would learn to make lots of different types of food.
- 3) Spend time with other people
 - You said that at the moment you live with your family, but it would be good to live with friends in the future.
 - If you live away from home, you hope to see your family “once or twice a month, maybe more.”
 - In the future, you think your friends will be a part of your life. You said that you would like to “go out for meals or nights out” with them, and that you might meet new friends at work.

Things that might get in the way of your plans

- 4) Physical health
 - You think that one of the things that might make it difficult to achieve the things you want to in adulthood is arthritis, as this impacts on your physical abilities.

Being a young person with ASD

- 5) Interests
 - You told me about some of your current interests, which include computer games, playing FIFA with your dad, watching football and cooking.
- 6) Spending time with others
 - You enjoy meeting up with friends, which you do every few months.
 - You said that you don’t have many friends living close by, but that you have some friends at college and have enough friends.

Support

7) Practical support from parents

- You spoke about your parents helping you out with some things, like claiming benefits. You said that without their help, you'd "find it hard."

Appendix 16: Respondent validation example (parent)

PRIVATE & CONFIDENTIAL

Aspirations and outcomes for people with autism spectrum disorders (ASD)

Summary of themes (Participant ID: MO08)

Aspirations for your child in adulthood:

- 1) Living independently
 - a. Your daughter hadn't spoken to you about living independently, and you had "always thought she'd be living with us 'til we go really." However, you found out that she had been saving to buy a house. You were pleased, and commented that it is "nice to think that she does... want to live independently."
- 2) Having a relationship
 - a. You hope that your daughter will "meet someone who'll be kind to her" and who will be "good to her."
- 3) More contact with other people
 - a. You encourage both your children with ASD to socialise, because "they miss out if they don't socialise and have friends," and hope that they socialise more in the future.
 - b. You added that it may not be that "they don't like to, they're just uncomfortable in that, because they're not very good... in social situations."

Possible barriers to achieving personal goals

- 4) Naivety of vulnerability to exploitation
 - a. You spoke about concerns that your daughter may be vulnerable in relationships, and you worry she has been exploited in the past - "I think he asked her... probably wanted more money off her and I think in her mind... they would end up getting married really."

Experiences parenting a young person with ASD

- 5) Difficulties in relationships with family
 - a. Some aspects of living with your daughter have been "hard" at times for you and her siblings as she "sort of rules" her siblings
 - b. It has been difficult for your daughter to get on with her sister following a seemingly small incident some time ago. You told me that, "She never talks to her to this day."
 - c. However, at times she gets along well with family members. For example, "I think in her way they do have a little bond there [your daughter and her brother] because they're quite similar."

6) Independent in some aspects of life

- a. In some ways, your daughter is quite independent, and learning to drive has been an important part of this; you identified the independence she has gained by having a car as one of the most positive aspects of her becoming an adult.
- b. You were not sure how your daughter might manage chores if she lived independently, “When she went to stay with her boyfriend she said she used to clean his flat but she never cleans anything at home.”

7) Interests offer some benefits and positive experiences

- a. Some of your daughter’s interests provide other benefits. For example, her interest in cars “was a good interest because she doesn’t do the social chit chat of other young teenagers, they had a bond in the car.”
- b. Her interest in working with animals has helped with symptoms of OCD. “I said to her... if you do want to do that, you can’t be worried about germs... So it’s actually got her over her OCD.”

8) Positive experiences of college and work experience

- a. Attending college has been a really positive experience. You have found the tutors at college, and colleagues at work experience to be accepting and supportive. “The tutors were really only a few years older than her and they were absolutely brilliant with her.”

Support received from parents

9) Parents provide practical support

- a. You provide practical support in a number of ways. One of the ways is buying toiletries, though this is difficult as you aren’t always told when things are needed - “She won’t tell me before she’s run out but she expects me to know that she’s running out and then she’ll get really angry.”
- b. Another way you offer practical support, is in assisting with your daughter’s online selling by posting packages to buyers.

10) Sought emotional support from parent

- a. Although your daughter does not often seek emotional support from you, you gave some examples of times when she had been very upset and had come to you for emotional support – “Like when she broke up with her boyfriend... she would come and sit on my lap like a toddler.”

Appendix 17: Extract from thematic matrix

	2.01	2.02 Spend time with others		2.03	2.04	2.05	2.06
	Education	2.02.1 Friendships and social relationships	2.02.2 Intimate relationships and children	Pursuing careers	Increasing independence	I just want him to be happy	Other
PA01 Parent Female	<p>"I have along the way tried to talk her into going back and doing things " (11283)</p> <p>"I actually tried to get her on a photography course but she didn't want to do it" (1681)</p> <p>"at one point she was looking at this course in America where they sort of you know you were working and learning all about tigers" (2235)</p>	<p>"I don't think it is that they don't want to socialise, but they don't know how to really. Which is a shame" (44499)</p> <p>"The thing that worries me with [yp] and [brother] is they'll end up just totally on their own" (43931)</p> <p>"I'd like her to have friends that are girls really but she doesn't seem to you know" (42638)</p>	<p>"Now that she's had a relationship I think it [being alone] might bother her more that it would before she had the relationship" (44277)</p> <p>"The thing that worries me with [yp] and [brother] is they'll end up just totally on their own" (43931)</p> <p>"I really hope she will meet somebody who you know can put up with her" (41364, 36896, 33735, 10686, 4725)</p>	Probably working with tigers (laughs), (4951)	<p>YP wants to live independently - found out after robbery. Had been saving</p> <p>"And in a way it would be lovely if she had her own house because it would make life so much easier." (45705)</p>	"But no I would like in the future I'd like, as long as she's happy whatever she's doing really. You know" (42508)	None
PA02A Parent Female	Parent did not comment.	<p>A bit of social contact would be good (38662) "what would be really nice if you could go somewhere like a kind of a youth club with people who are a bit like-minded " (37505, 36677, 21445, 21092) "I wouldn't want him to be...to feel lonely" (18101)</p> <p>"I would envisage that you know, one or other one us would be...keep in quite close contact with [yp]. [R: Okay]. I would hope so anyway, because I think we're qui...you know...I think...without overwhelming him" (16770, 16107)</p>	Relationships are tricky at the best of times (22274)	<p>and I think that's probably the best thing is to find something to do in life that you enjoy. Whether it's being a chef or not, I don't know 5151, 4107,</p> <p>I think that's what would be nice about having a job or something to do is that you'd be with other people 21092, and not bored 36021, 38662</p>	<p>"basically, I hope [yp] will be able to get a house perhaps at some stage in the future...maybe, I don't know...I haven't thought when. In 10 years, maybe?" (11414)</p>	<p>"I just want him, to to feel um, happy and content with his life" (21839)</p> <p>"I'd love for him to find something that he loves...likes doing" (5066)</p>	<p>"what would be really nice if are you know, are make sure you're ha-you're well, you're fed, you're...you don't just just of...just sort of the basic things. Those are the most important things aren't they" (35421)</p>

PA02B Parent Male	<p>Education provided in a way that is sensitive to ASD and trains for a specific job (18101, 15795)</p> <p>"it also where the education might be about how the helping him to become more aware of how his autism is affecting him [R: Mm.] and how he might develop strategies to understand himself better and better and enable to deal with society" (15795)</p> <p>Hopes yp will become more proactive in finding training (2146)</p> <p>"there's a bit of him that quite likes the idea of you know, doing something mechanical." (673)</p>	<p>Social contact, a friend or two, or someone to come and take him out that he could develop a relationship with (24026, 8766, 6670, 4335)</p> <p>"I think his life would be a lot better if he was able to form friendships because otherwise you get terribly lonely, and although he may not suffer as much as some people" (21825)</p> <p>"He doesn't realise, I think, that, that he would get a lot if he could have a relationship, if he could have a friendship" (10187)</p>	<p>"I would have thought he would, I mean he's...he hasn't...it's not a thing we've talked about with him much. Um, and he hasn't...he hasn't had any girlfriends or boyfriends or anything so in a partner's sense...so, I don't know. I would guess...I would guess if it could happen, it would be great if it could happen, but then that's true for everybody, you know. If anybody can get a really close, loving relationship that's brilliant" (22544)</p> <p>"certainly he needs a relationship but I don't think he needs to have a family of his own" (21565)</p>	<p>a job 6670, "even if it's only voluntary work" 8766</p> <p>"meaningful activity where he feels he could...he'd have a job to do and he can achieve something" (8766)</p> <p>"at one time he did have an ambition to be um, a chef. And he still has that ambition but I think it's more...it's more like....a habitual response now" (18501), "I don't think he could go into a commercial kitchen" (19307)</p> <p>"have a job to do and he can achieve something and he can get something done and he can feel you know, a bit of pride in himself" (9598)</p>	<p>"hope that he's able to fend for himself. I hope that he's able to look after himself and have a social life and have a life. You know, and I hope that he doesn't fall apart when we're gone and have to be institutionalised or anything like that. " (4335)</p>	no data	no data
PA03 Parent Female	<p>Parent did not comment.</p>	<p>"How important is it for you, or how much do you think about her relationships with other people?</p> <p>P: A lot. Because I don't think she always, she's a very kind, very caring girl. " (10975)</p>	<p>"I suppose I'm fearful that he... although he handles it now he might not be able to handle it forever." (16216)</p>	<p>"she's, she's very committed to getting a job. Um even though that's going to be incredibly difficult for her and I would rather she didn't work at the moment!" (4602)</p> <p>"I would love her to be um in work" 5609</p>	<p>"Do you think independence is important from her perspective? P: I do, and from ours." (21866)</p> <p>"it would be nice if we could have that piece of mind that she wouldn't um uh struggle if we weren't here." (6596)</p>	<p>"I suppose it's a bit cliché, but good health and happiness I suppose! " (38219)</p>	<p>"I want her to know that it's alright for her to do things her way." (39029)</p> <p>"She doesn't want to be in pain." (38371)</p> <p>"definitely the main thing would be if she didn't have the arthritis because that really debilitates her in all sorts of areas" (3410)</p>

Appendix 18: Respondent validation form

Aspirations and outcomes in people with autism spectrum disorders (ASD)

Thank you for taking part in this study. We would be grateful to hear your feedback on the themes that have been identified from your interview. Please complete this form and return it in the envelope provided. Alternatively, you can complete this form online at <https://opinio.ucl.ac.uk/s?s=22309>

Name:

Date:

How much did the themes listed capture your views from the interview?

0	1	2	3	4
Not at all	A little	Moderately	Quite a lot	Very much

Things I think are missing:

--

Things that need changing:

--

Any other comments:

--